

MS *in focus*

Issue 3 • 2004

- Special Focus
on the Family



multiple sclerosis
international federation

Multiple Sclerosis International Federation

Established in 1967, the Multiple Sclerosis International Federation links the work of national MS societies worldwide.

We are committed to working together and with the international research community to eliminate MS and its devastating effects. We also speak out on a global level for those affected by MS.

Our priorities are:

- Stimulating global research
- Stimulating the active exchange of information
- Providing support for the development of new and existing MS societies

All of our work is carried out with the complete involvement of people living with MS.

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Letter from the Editor



Learning to cope with a chronic illness such as multiple sclerosis is not only a challenge for the person who has been diagnosed, but also for everyone who cares about that individual, especially family members. We have learned from experience and research that MS can have significant effects on a person's role within the family, on the relationship between parents and children and between partners. Inevitably, it impacts on the general balance and well-being of the family as a whole.

Given the potential negative influence of MS on the family, we have dedicated this issue to a detailed discussion of a wide range of aspects, including making the decision to have children, talking about MS, changing roles, care-giving and a number of other relevant topics related to the family.

We present topics that are often difficult to discuss, for example, divorce or abuse in the care-giving relationship. Often it is only through frank discussion that we can truly understand the seriousness of such problems. I hope that our *MS in Focus* readers will appreciate the importance of including these sensitive issues.

The Editorial Board has done an outstanding job of making this third issue truly multi-national. We have invited contributions from authors in eight countries, and have made an effort to ensure that the information and strategies presented are not culturally or geographically limiting, but hold true for families dealing with MS around the world.

The aim of this very special issue of *MS in Focus* is to let families know that they are not alone in coping with this disease, and that many challenges they may be facing today, or may face in the future, can be successfully confronted through open communication, understanding and correct information.

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 Emotions and Cognition. Send questions and letters to michele@aism.it or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Vico chiuso Paggi 3, Genoa, Italy 16128.

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 healthcare professional. For specific, personalised information, consult your healthcare provider. MSIF does not approve, endorse or recommend specific products or services, but provides information to assist people in making their own decisions.

What is it about MS that makes it a 'family' disease?

By Rosalind C. Kalb, PhD, Director, Professional Resource Centre, National Multiple Sclerosis Society, USA

The vast majority of people who have multiple sclerosis are diagnosed between the ages of 20 and 50 years. The disease thus affects people in their most productive years: young adults readying themselves to leave home in pursuit of academic, vocational, or social goals; men and women in the process of launching careers and families of their own; and those in middle age who are enjoying their productive years and planning for their retirement.

Since MS has little impact on life expectancy, it is likely the person diagnosed will be living and coping with its effects for many years. MS has often been compared to the "uninvited guest" that arrives at the door one day, complete with baggage, and never goes home. It moves into the household, using up space in every room of the house, and taking part in every family activity. Every person in the household needs to learn how to live and cope with this uninvited guest.

MS is unpredictable. Individuals with MS and their family members may have difficulty anticipating what the next day or week will bring, let alone the more distant future. Planning becomes difficult, creating an ongoing need for flexibility and creativity.

MS is expensive in different ways. In addition to the financial cost of MS, there is a costly drain on other family resources as well, including time, energy, and emotions. Families living with MS face the daily challenge of trying to distribute these valuable resources appropriately among all family members.



Each family will develop a rhythm of its own.

Living with MS poses an ongoing challenge to the emotional equilibrium of a family. The person with MS *and* family members experience feelings of loss and grief with every new symptom and each change in functional ability. Any progression in the illness requires family members to adjust to the loss, and to redefine themselves and the family accordingly. Anxiety and anger are commonly experienced by families as they try to cope with the uncertainty, change, and loss that accompany MS.

Challenges to family coping

Families' efforts to cope with the intrusion of MS into their lives are challenged, not only by the complexities of the disease, but also by the

complexities of the families themselves. What is it about families that complicates the coping process?

The family unit is made up of individuals, each with a unique personality and coping style, as well as age-appropriate needs and goals. Each person in the family will see the MS in a slightly different way, and respond to its demands in terms of the way it impacts on his or her particular situation. Therefore, the family's efforts to deal with the disease cannot be seen as a unified, coherent process, but rather as the sum total of individual, sometimes conflicting, coping efforts.

The family's response to the MS is not a simple one. At any given point in time, it is a reflection of the feelings, attitudes, needs, and priorities of each of the people involved.

Disruption of the family's rhythm

Over the years, families tend to develop a rhythm of their own – a reasonably smooth and predictable way of carrying out the routines of daily life, with each member having specific responsibilities within the family. If one person in the family becomes unable to carry out his or her particular role(s), the rhythm of the entire family is upset. Whether it is recognised at the time or not, this shift in roles begins to change the ways in which family members interact and communicate with one another.

Disruption in family communication

Talking about these kinds of changes within the family can be very difficult for a variety of reasons. First, since changes tend to happen slowly, families may not be sufficiently aware of their impact to discuss them as they begin to occur. Second, people often have difficulty talking about changes in family life that are caused by symptoms they cannot readily see or understand. MS-related fatigue, sensory symptoms, and cognitive changes are difficult to describe to others; they are easily misinterpreted by family members who cannot understand why family life is not proceeding as smoothly as it once did. Third, family members tend

to be quite protective of one another, with the result that painful feelings, questions, and concerns are often left unexpressed. And fourth, people sometimes feel that “the less said, the better”, as though talking about problems will confirm that they actually exist, and not talking about them will make them magically go away.

Important resources and barriers to their use

Fortunately, a variety of resources exist to help families live well despite chronic illness. Healthcare teams, voluntary health organisations, educational materials, and various types of professional and self-help groups are some of the tools available to support families' coping efforts. Unfortunately, there also seem to be significant barriers to the effective utilisation of these resources.

Some of the barriers are social and economic while others are much more personal and emotional. Access to quality healthcare is not universal, and access to professionals with expertise in MS is even more limited. In addition, many people do not make use of important resources even when they are readily available. Many families may not want to acknowledge the potential impact of MS on their lives, or to think about MS more than is absolutely necessary; some are afraid that thinking about current or potential problems will somehow make the problems seem more real. Other families seem to feel that seeking outside help or support would be an indication of their own weakness or inadequacy. They do not recognise that these resources are the kinds of tools that might enable them to manage more effectively.

Becoming educated about the potential impact of MS on the family, and taking steps to protect the family's financial, social, and emotional well-being, can help each person feel less vulnerable in the face of this unpredictable disease.

** The above article is based on Chapter 1 of Multiple Sclerosis: A Guide for Families, edited by Rosalind C. Kalb, 1998, Demos Vermande, New York, USA. ISBN 1-888799-14-5.*

How to encourage your children to talk about MS

By Marianne Nabe-Nielsen, Senior Psychologist, MS Society, Denmark

MS causes many concerns for a family. A major one for a parent has to do with the question of when to tell children about the diagnosis, and how to explain MS so that they can understand.

When parents are troubled, children sense this and need to understand what is happening. Parents may be reluctant to talk about MS in order not to worry the children. This, however, may cause uncertainty and fear, and may also discourage children from asking questions and talking about delicate, important matters that may be bothering them. By contrast, open communication will encourage an honest and shared approach to facing the challenges of MS as a family, which can, in turn, help the child to cope.

Every child and every family is unique. Accordingly, there is no one simple recipe for how to talk to children about MS. However, a few general guidelines and good advice can be of use and inspiration to parents.

Before the diagnosis

Even when there are no visible symptoms, children are sensitive to physical and emotional changes in their parent. They sense that something is going on, or that something is not right or normal. It can be reassuring for the child to be told that the parent is being helped by excellent doctors to help figure out why mum or dad is not feeling well.

Explaining MS

For some families it may be helpful to have all of the family together when talking about MS with the children. A shared experience may make it easier for the child to confide in other family members with whatever thoughts and worries

may arise in the future. Other parents may prefer to speak individually with each child.

Facts about MS should be presented a little bit at a time without too many details, and without talking about possible, future consequences – as they are, in fact, unpredictable. It is not negative for the child to witness the parent's feelings. On the contrary, this may help the child feel more comfortable about sharing his or her own feelings.

Children may not ask questions spontaneously or talk about their thoughts and feelings. If this is the case, questions from the parent can be helpful in better understanding what the child is thinking, as well as whether he or she has understood the explanation about MS. However, it is important not to push too hard. Children typically do not need long explanations, and often respond and ask questions gradually when they feel the need to know something.

A number of MS societies offer age-appropriate booklets about MS that may be helpful in accompanying a parent's explanation about MS.

“When mum told us she had MS we became very scared. Then papa told us that you do not die from MS. We wonder if they are honest.”

Siblings, 9 and 11 years

Age and ability to understand

Generally, children are quite capable of coping with stressful events as long as they understand what is happening at their own level, and they feel that the problem is being dealt with. Their

reactions and what they need to know will depend on their age and ability to understand. Children younger than four years are influenced primarily by changes and disturbances in their everyday life. Typically, they are not comforted by explanations and do not comprehend the implications of MS. Their well-being depends on a safe and familiar daily life where their needs are attended to. Physical contact and care are more reassuring than words.

“Mum went to hospital when I was five years old. I thought she was going to die because grandmum died there. I was afraid but I did not tell anyone.” *Christoffer, 10 years*



The same applies for pre-school children (four to six years), but at this age children also benefit from brief and simple explanations and examples. As smaller children are active with vivid imaginations, they may believe that they are to blame when their parent is tired, or when the disease seems to worsen. Children at this age need to be reassured that their actions do not influence the disease.

Children from the age of approximately six are able to understand, and perhaps notice more. They may become very insecure about their role in the family, and may have a tendency to take on too much responsibility within the home. They regularly need to be reminded that they are not to blame, and that they are not the adults in the family. Like younger children, children in this age



Focus on the things you can do together as a family – MS or not.

group need attention and care, but also benefit from helping to give care and to feel useful. Parents should encourage children to help with smaller, practical chores, but never let them take on the adult's role.

It is well known that teenagers in families with MS are at risk of taking on too much care-giving and too many practical responsibilities. The teenage years are a time for seeking one's own identity and independence from the family. However, it may be difficult to focus on one's own interests and relationships, if the family's situation requires that the teenager takes on responsibilities within the home, and even for the parent with MS. In this situation, the best support is given by showing that the parent can manage without the teenager taking on too much responsibility, and by encouraging them to engage in their own lives. For this to occur families need to be informed about available resources that can help them organise care and household tasks in a way that will not overly burden any one member of the family, especially a child.

“I realised that I can have fun and be happy at the same time as all the serious things.” *Lisa, 14 years*

Children of any age may worry that their parent could die from MS. Also, older children may worry about getting it themselves. These concerns may come up in situations where the child did not

receive appropriate information at the beginning. In order to confront these fears, it helps if the child feels that he or she can express them to the parent or to another person who is available to listen. MS society websites, support groups and informative literature may be helpful resources for older children with these types of concerns.



Open communication can help a family deal with MS.

Importance of having a confidant

Children often spare the ill parent their more difficult questions and negative feelings, such as anger or shame. Often such feelings are taboo and encumbered with guilt. Therefore, it can be of great importance for children to have a relationship with another adult, for example, another family member or a teacher who is close to the child. Having the parent suggest this kind of contact may encourage the child to take advantage of having another person outside of the "MS situation" as a confidant.

School and spare time

The children of a parent with MS may feel that their life is so very different that others will not be able to understand them and know how they feel.

One way to help the child in talking openly to others about MS is to present simple explanations about the disease and life with MS



The teenage years are a time for seeking one's own identity and independence from the family.

so that the child has information to use when peers ask questions or make comments. It is also helpful for parents to inform and educate teachers about MS so that they can better understand a child's home situation.

Open communication – on a long-term basis

Over time, the disease may increasingly affect more aspects of family life, requiring additional effort to maintain the well-being and quality of life of all members in a family. Keeping communications open can help a family deal with the emotional pressure of living with MS. Family meetings on a regular basis can help to identify the practical, as well as personal and social, needs of the family as a whole, as well as of each individual member. Families should be encouraged to enlist help from outside if at all possible, so that no one family member is overly burdened with either personal assistance or household duties.

An essential element for communicating with children about MS is acknowledging that each child has his or her own needs and capacity for understanding, based on age, among other factors. It is important to talk honestly about MS, from the beginning, at a level appropriate for the child's age.

"I would like to go on summer camp, but how can they manage without me?"
Anna, 17 years

Changing relationships and roles within the family

By Roberta Litta, Psychologist and Family Psychotherapist, Italian Multiple Sclerosis Society National Headquarters, Genoa, Italy

Partners changing roles

Since MS may affect the way a person functions physically, often making once easy activities more difficult, it can become necessary for the members of a family to change roles within their family system. It may also be necessary for the couple to exchange roles. For example, the traditional family supporter may find him or herself responsible for tasks around the house that were previously taken care of by others.

If the partner has to take on responsibilities for personal care, especially without any support from others, the partner can be at risk of burnout. When a partner assumes these types of duties the couple may be at risk of compromising their relationship as a couple as well. This can happen when the person with MS requires extensive personal care, such as bathing, feeding and help in the bathroom, performed by the spouse. It is often difficult for the couple to maintain an intimate relationship in this case. Utilising outside assistance for very personal care duties may be helpful. When this is not possible, the couple should be encouraged to receive counselling in order to learn ways of maintaining their intimacy.

Changing roles within a partnership can create feelings of resentment and anger, especially if one or both members of the couple feel forced into making changes. Couples should be encouraged to discuss how certain changes would improve or disrupt their lifestyle and relationship. When communication problems exist within the partnership that hinder an open discussion of role changes, it is helpful to involve a professional counsellor or psychologist.



Older children with a parent with MS should be encouraged to express their concerns about changing family roles.

Children changing roles

When a parent is unable to continue performing tasks within the home, often the children are expected, or needed, to take on the responsibility



The original parent-child relationship may need renegotiating.

for certain tasks. Helping with some household jobs and with giving assistance to the parent with MS is acceptable. Children of a disabled parent often grow up to be particularly sensitive and caring adults.

However, it is important for the well-being of the child that certain personal assistance tasks, such as helping in the bathroom, are handled by an adult family member or personal assistant. Children should not be expected to sacrifice their childhoods for the needs of the parent. Other resources should be taken advantage of to avoid putting too much of a burden on a young child.

Adult children with MS changing roles with their parents

In some situations a person with MS may find it necessary to rely on parents, or even to return to the childhood home. For an individual who is accustomed to being independent and self-reliant, the need to ask one's parents for help, financial or otherwise, can impact on self-

esteem and create feelings of guilt. This may be even more evident for a person with MS who has elderly parents with their own health problems.

While some parents may feel the need to protect their "child" who needs them, over-protectiveness can cause resentment and anxiety. It is important to keep in mind that, for a parent to have a child with a disease like MS, coming to terms with the implications can be quite difficult. These parents may experience overwhelming concern, anxiety for the future and even guilt.

The type of role changes that occur between an adult with MS and his or her parents require open communication, flexibility and honesty on the part of every person in the family. Each person in the family must express personal needs, while respecting those of other family members, with the acknowledgment that the original child-parent relationship may need renegotiating.

The impact of “invisible” symptoms on the family

It is estimated that as many as half of people with MS experience mild cognitive problems. Because cognitive difficulties in MS are “invisible” symptoms, family members may misinterpret the behaviours or reactions of the person with MS. Difficulties with memory, problem solving and concentration may be interpreted as not caring or not listening, being uninterested or unwilling to cooperate.

Information provided by healthcare professionals must include a discussion of cognitive problems, including what types of problems are directly related to MS, and which strategies can be used by the individual to overcome any difficulties in daily life that may be the result of these problems. Correct information can be the key to helping families understand and cope with cognitive problems.

Fatigue is another misunderstood, often misinterpreted, invisible symptom of MS. Often a family member with MS appears to lack motivation or to be lazy when, in fact, the person is experiencing MS fatigue, a type of tiredness or exhaustion that is a symptom of the disease (see *MS in Focus*, Issue 1 on managing fatigue). When the family has a clearer understanding of MS fatigue and its impact on the person's ability to function, they may be more keen to help out with household tasks, to reconsider family activities that may be strenuous for the member with MS and, in general, reorganise the house and habits of the family in a way that helps the person with MS conserve energy. It is important for the family to understand that energy conservation strategies can help the person with MS have more energy to spend with the family.

How families cope

Each member of a family has his or her own coping style. On finding out that a family member has MS, some individuals look for as much information about the disease as they can find,

and perhaps prefer to talk to others about their experience with MS. Others in the same family may deal with news of the diagnosis by keeping busy with other activities in order to avoid thinking about MS. Each person brings into the “MS experience” his or her own way of coping. Different coping styles within the same family can be complementary or contradictory. Contradictory coping styles may lead to conflict within the family.

Family members should be encouraged to cope with MS in their own individual styles, while respecting the coping styles of other members. However, communication is key, and if a family traditionally has dealt with problems by ignoring their existence, assigning blame or using some other, ineffective strategy, the family's way of confronting MS is likely to be destructive, at least without the help of a family counsellor or psychologist.

Separation or divorce

The few studies that have looked at divorce have produced contradictory results. We do know that MS can add stress to a relationship. The unpredictability and progressive nature of the disease, the changes and sacrifices that might be required, symptoms and so on, are all obstacles that make it difficult for both the person with MS and the partner to cope. It may be useful for a couple to seek help from a counsellor even if they are not in a crisis, so as to keep communication open and to discuss difficult issues as they arise. This could help them to avoid reaching a crisis from which it could be difficult to recover the relationship.

MS affects every member of the family. Learning about the disease and its possible effect on the family can help in being prepared to face challenges as they arise. Families that are informed about the different resources available can choose those that best suit their needs and lifestyle.

Caring for the carers

By Deborah M. Miller, LISW, PhD, Director of Comprehensive Care, Mellen Center, Cleveland Clinic Foundation, Cleveland, Ohio, USA

Carers are individuals who assist with the physical, emotional and daily management needs of people who cannot take care of all of those activities on their own. Carers can be either paid professionals, such as the staff of home care agencies, or informal carers, including family, friends or members of social or religious groups who provide the help without any financial compensation. This article will focus on family carers.

There are times in most people's lives when they expect to be care-givers, for example when becoming a new parent or becoming more involved in helping their aging and frail parents. In the first situation, the parent care-giver looks forward to the experience of caring for the child. In the second situation, neither the adult child nor the aging parent want the need for caring to happen, but typically both the care-giver and care recipient have time to prepare for this and they see many of their friends and family members adapting to the same situation. Because MS can cause disability at a time when most people are in the prime of life, their carers have little time to adjust to this responsibility and have few other family members or friends who share their care-giving situation. Often, care for a person with MS is required on a long term basis, possibly becoming more demanding as the care receiver's needs grow.

For persons with MS, carers are most often spouses, young children living in the home, adult children living either at or away from the home, or aged parents.

Care-giving involves several types of activities. The type that most often comes to mind, "hands-on help", can include typical housekeeping chores or more intimate kinds of help like

bathing, dressing or helping to use the bathroom. Some of these chores can be taken care of on a routine schedule. For instance, the house gets cleaned every Monday or the week's meals are prepared on Wednesdays and Saturdays. Other responsibilities, like helping to go to the bathroom, are completely unpredictable and must be addressed with alternative solutions, especially for those times when the carer must be out of the house.



Sometimes listening is most important.

Another aspect of care-giving is emotional support. Often, the person with MS is very socially isolated and has few other contacts besides the family carer. Sometimes the most important help a carer can provide is being there to listen to the frustrations of the MS person about their loss of independence or not being able to care for the house by themselves. It can,

at times, be frustrating, as the source of the MS person's frustration may be about the quality of "hands-on" assistance that the very same carer is providing. Helping the MS person "manage" his or her life by helping or taking over personal finances, or making decisions about hiring and supervising paid carers is another type of care-giving. This type of care-giving can be welcomed either with relief by the person with MS or met with suspicion and frustration that the carer is taking over.

Whether the family carer is a spouse, a child or a parent, taking on such a responsibility has an impact on their other responsibilities, their health and their relationship with the person with MS. This change in relationship most often occurs as the carer becomes more powerful and the person with MS becomes more dependent. For married couples, in particular, this imbalance makes it more difficult to maintain a romantic relationship. Often parents with MS feel that their positions as parents are compromised as they turn to their children for help in meeting their daily needs. And when an adult child turns to an aging parent for care-giving help it seems that their relationship often becomes more complicated as they fall back into the patterns of relating that they had 20 years earlier.

While many family members welcome and adjust very well to the caring role, the responsibility produces some level of physical stress and emotional strain. The physical stress can result from the activities of caring, including helping with transfers or the fatigue that comes from lack of sleep. The emotional strain often begins with the sorrow that the carer experiences at the changing relationship with the person with MS and their grief at the constant losses in physical and cognitive ability their loved one experiences as MS progresses. Many carers believe that it is much easier to deal with the physical changes than it is with the cognitive losses that "take away" the person they love. Other sources of emotional strain are the multiple responsibilities that the carer must manage and the social isolation that results from these many demands.



Caregiving involves practical hands-on help and emotional support.

Most family carers have many responsibilities in addition to the help they provide to their family member. One of the biggest conflicts that carers face is the need to work. This is essential to meet the needs of their family, and to pay for all the MS-related expenses that are not covered by insurance or a national healthcare system. Because of this need to work for pay, many carers find themselves managing two full-time jobs, their paid employment and the caring, with too little time for being with other family members, seeing friends or participating in church, social or political activities. This leaves them with too many responsibilities and no chance of doing any of them well.

Some carers find themselves drained and frustrated because of the many physical and emotional demands upon them, and have little opportunity to re-energise themselves. This combination can be very dangerous for both the carer and the person with MS and, at times, results in the carer becoming neglectful or abusive. Sometimes it can be passive, by not helping to clean up the family member who has obviously had a bladder accident. Abuse may

DEFINING THE HELP YOU NEED

How many times have you heard someone say: "If there's anything you need" or "If there's anything I can do". And how many times have you, as a family carer, actually said "Well, as a matter of fact...". If you're like most carers, not many. Being a healthy family carer means asking for and accepting help, although it may not always be easy.

The list below can assist you in defining and getting the help you need.

Seven Steps to Getting Help:

1. Recognise that care-giving, like all jobs, is made up of lots of individual tasks, not all of which are of the same importance.
2. Understand that asking for help is a sign of strength and not of weakness.
3. List all of your care-giving related tasks that need to get done during a typical week.
4. Group your list into categories: personal care for your loved one, transportation, household chores, healthcare activities.
5. List your care-giving worries (for example, who will care for my loved one if I get sick? What will happen to my loved one if she falls when I'm not home?)
6. Show your list to a family member, good friend, the MS nurse, etc. to get further ideas and insights. The intent is first to get comfortable with the idea of talking about your need for assistance, and hopefully get some encouragement and good ideas in the process.
7. Finally do it! Take a deep breath and actually ask someone to help with one of the tasks on your list, or ask for guidance in resolving your most persistent worry. Start with something small, but start!

If your request falls on deaf ears at first, try not to get discouraged. It sometimes takes perseverance. Just remember, the effort is worth it because the goal is better care for your loved one and yourself.

**Adapted from US National Family Caregivers Association (NFCA), Defining the Help you Need, 2003. www.nfcacares.org.*

start in a seemingly innocent manner, perhaps by pushing or pinching during a transfer, or scrubbing too hard while giving a bath. Sometimes the abuse can seem to come out of the blue, as happened when a husband poured a cup of boiling tea on to his wife's lap rather than place it on her tray because she had been "too demanding".

While it is easy to understand how stressful care-giving can be, abuse or neglect is never acceptable.

When a carer feels him or herself "burning out" it is essential to get help from other family members or medical professionals. (See box opposite for tips on avoiding carer burnout.)

WAYS TO AVOID CARER BURNOUT

As MS progresses the carer role can become more involved. It is important to take steps to avoid becoming burned out. Below are some tips to help you along the way.

1. Set boundaries. As a carer you have enough to do already. Don't feel like you have to say "yes" to the requests of others.
2. Set realistic limits. Accept that you cannot do it all. No one should expect you to. You should not expect it of yourself.
3. Delegate responsibility and create a care team. If you have others around you who are willing to help, take advantage of it.
4. Seek and accept help. If you have realistic limits you'll know when it is time to ask for help – ask before you find yourself in a crisis. If someone offers help, take advantage of it.
5. Celebrate success. Celebrate your own success, no matter how seemingly small. Celebrate the successes of your loved one.
6. Take breaks. Taking periodic breaks to do something that gives you enjoyment and peace, even if it's only a 10-minute break, can help recharge you for the rest of the day.
7. Utilise respite care and adult day care. Accept that getting away from the care-giving situation helps you and your loved one. If you feel guilty about leaving your loved one talk your feelings over with someone.
8. Identify what external resources are available, including carers' training courses and physical aids.

Resources for people dealing with MS day-to-day will vary from country to country. In each case the National MS Societies will be able to help carers identify what is available.

** Adapted from The Well Spouse Foundation website, 2000. www.wellspouse.org*

Most family carers are committed to caring for their family member with MS and consider it an act of love much more than a family responsibility. There are several keys to maintaining one's capacity for caring. One of the most important is having the best possible communication with the person with MS. Maintaining this effective communication means being able to talk about the practical aspects of dealing with the MS, as well as the emotional

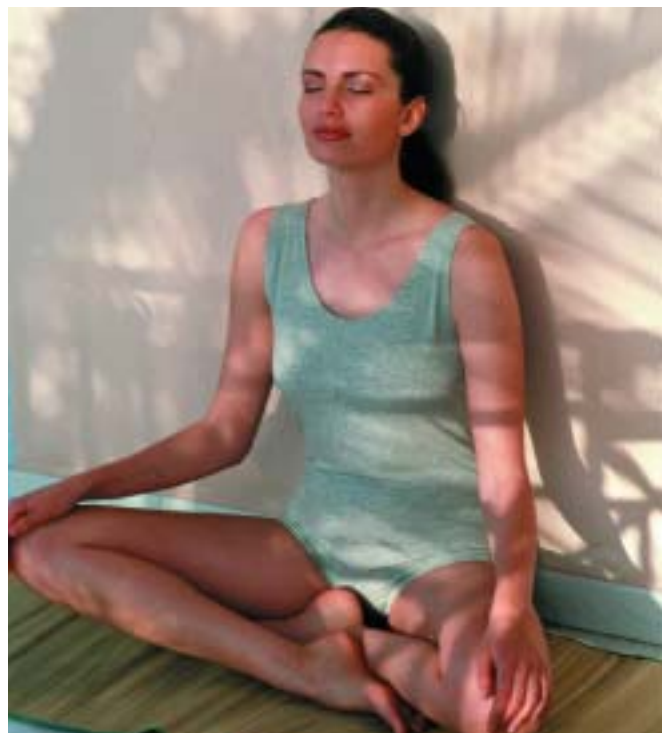
consequences both family members experience. This could involve the ability to have potentially difficult conversations, for example, about the carer's need to maintain some of the activities that the couple used to share. It can be difficult to maintain this positive communication as so many unwanted changes occur within the relationship. For this reason, it can be very useful to receive counselling from a mental health professional. Such a professional can assist with

developing good communication techniques, such as identifying the best time to have potentially difficult conversations, not blaming the other person for one's own feelings, and the most positive way to frame what needs to be said. Sometimes these professionals are helpful in facilitating especially difficult conversations, for example about the need for outside, paid help, the need for adult day care or the possibility of a nursing home.

Being informed can help the carer take advantage of available resources that might improve the care-giving experience. For example, learning how to provide care in classes that train in transfers, injections, bathing and bowel and bladder programmes are offered by some national MS societies or other organisations. Also, knowing what types of equipment, appliances or renovations are available, and how to evaluate and choose them might ease physical demands of care-giving and provide the person with MS more autonomy.

MS is a disease that lasts a lifetime. The need for care seldom, if ever, is reduced over time. In order for family members to continue their caring it is essential that they take care of themselves just as well as they care for the person with MS. This includes open and honest communication with all of the family about the care-giving situation and about the need for help if that

arises. It is all too common that carers make sure the person with MS never misses a medical appointment, but never have their own appointments. Maintaining one's own physical and emotional health is a key to sustaining positive caring. Carers should know when to ask for help, make sure that they have ways of keeping themselves refreshed, and take advantage of the services offered through their local chapters of the MS society, such as peer support groups or respite services.



Carers must give themselves time to re-energise.

COMMUNICATIONS BETWEEN FAMILY AND HEALTHCARE PROFESSIONALS

It is common for family members to be present during visits to the neurologist, nurse, therapist, etc. Often this is very helpful, especially when the patient must learn a new technique or receive new information. However, in some situations the family member can become an obstacle during the visit, especially if he or she tries to answer questions or contradicts the patient. The healthcare professional must respect the patient's choice to have family present or not, and should avoid communicating information about the patient to the family without the patient's consent, which is illegal in many countries. To help the visit go smoothly, families should prepare their questions beforehand and write them down. It should also be agreed upon before the visit that the person with MS is responsible for answering his or her own questions and providing information to the professional.

Pregnancy

By Nicki Ward, Lecturer Practitioner in Multiple Sclerosis, University of Central England, UK

Even in the 21st century, some women with MS still report that they are met with either negative views or inaccurate information when asking questions about both pregnancy and childbirth. This short article aims to dispel some of the myths and misconceptions surrounding this area and to provide up-to-date, accurate, evidenced-based information for women with MS who are currently pregnant or who are considering starting a family.

The effect of pregnancy and childbirth on women with MS

Prior to 1949, women with MS were advised to avoid pregnancy as they would make unfit mothers, their MS would progress disabling them further and they could pass the disease on to their baby. Further studies have long since dispelled these myths and the advice given to women is now very different. Research has proven that the long-term course of MS is, in fact, unaffected by pregnancy and most mothers with MS are perfectly able to care for their babies if they are given support.

Studies of pregnancy in women with MS have discovered that relapse rates are affected both during pregnancy and in the early postnatal period. The risk of relapse during early pregnancy probably will not alter, but there is a lower risk during the later months of pregnancy. The first three months after delivery pose an increased risk of having a relapse but then relapse rates will return to those of pre-pregnancy.

Most women feel well during pregnancy and the majority will not experience any new problems. There is a possibility however, that for some



women some symptoms already experienced, such as fatigue or bladder and bowel problems, will worsen. The diagnosis of MS should be discussed with the medical professionals dealing with the pregnancy and delivery at the start, and these medical professionals should have access to the MS professional. Any changes or increases in symptoms need to be discussed with your doctor, midwife or MS nurse.

Can MS be passed onto an unborn child?

MS is not an inherited condition, although there is a slightly higher chance of a child born to one parent with MS developing the disease compared to the average population. This chance is considered to be low, and is estimated at between one and four per cent; this should not discourage a couple from having children (see page 20). Genetic counselling is not available yet as there is no identifiable gene strongly associated with the development of MS.

How to manage drug regimens when planning to become pregnant

It is important to discuss medications before becoming pregnant, as some that are used in MS may be harmful to the baby. Generally, steroids are best avoided during pregnancy but under certain circumstances, for example if a severe relapse is experienced, the neurologist may decide the potential benefits outweigh the small risks.

Women taking disease modifying drugs (DMDs) such as beta interferon or glatiramer acetate, are advised to discontinue them three months before stopping contraception. Although some women

have continued to take them during pregnancy and have had perfectly normal pregnancies and babies, this is not recommended in general practice. Interferons are known to contain properties that can increase the risk of spontaneous miscarriage. They can be recommenced safely once the baby is born and the woman is no longer breast-feeding. If a woman on DMDs becomes pregnant unexpectedly, she is simply advised to stop taking them straight away; they will not require any special treatment or observation.

Breastfeeding

Breastfeeding has no negative effects on MS. Some small studies carried out recently even suggest breastfeeding could have a positive effect on the disease. This is still under investigation and has not been confirmed.

If a mother is experiencing problems with numbness or weakness in her arms or hands, positioning to feed the baby may be difficult. It is important to discuss such problems with the midwife or MS nurse, as they will be able to offer suggestions and advice on how to manage this.

Planning for a baby

When planning pregnancy it is important to consider:

- Eating a healthy diet, taking regular gentle exercise and giving up smoking and alcohol before and during pregnancy
- Taking folic acid before conception and three months into pregnancy
- Speaking to the doctor regarding medication or any supplements that are taken
- That women with MS should not routinely require a caesarian section
- That women are able to receive an epidural or use a TENS machine (transcutaneous electrical nerve stimulation – a method of treating persistent pain that applies electrodes to the skin) if this is recommended
- Planning with your partner who is going to do what in terms of household tasks, baby tasks, etc.

- That you do not have to cope alone. It can be helpful to highlight potential sources of help (such as family members and friends) who will provide support if it is needed
- A relapse may occur during the first few months after delivery and this needs to be discussed and planned for
- Talking does help relieve stress. Talk over any anxieties with your partner, a friend or your midwife. Attend a local support group for mothers
- That fatigue levels may increase during and after pregnancy, and this can interfere with parenting activities. Ask your therapists or nurse about energy conservation techniques
- Searching for aids and equipment that will make life easier

Conclusion

Pregnancy for any woman can be stressful, but there are even more worries and anxieties for the woman who also has to live with MS. Education with accurate and up-to-date information is essential to help reduce some of these anxieties and to dispel many myths associated with pregnancy and childbirth. MS is well known for being unpredictable, and consequently a woman with MS has more reason than most to plan well in advance both for her pregnancy and for the potential practical support that may be required once the baby is born.

Will my baby have MS?

“Simple risk estimates are oversimplifications which can easily be misinterpreted. The reality is that risk estimates may be very different depending upon family structure. We now know that risks are much higher for families in which MS occurs in multiple relatives than for families in which there is only one affected individual. Risk is also moderated by ethnicity and by other factors we haven't yet pinned down.” Dr. Stephen Hauser, MS Centre, Department of Neurology, University of California, San Francisco USA

Children can get MS too

By Professor Folker A. Hanefeld, MD, Paediatric Neurologist,
Georg-August-University, Göttingen, Germany

When MS was "discovered" in 1874 there were doubts about the existence of the disease in childhood, and for almost 50 years the existence of childhood MS before the age of 10 years was ignored or denied. However, with the advent of modern research techniques it became possible to differentiate between various causes of demyelination, which helped build the case for the possibility that a child could indeed develop MS, although, so far as is known today, true childhood MS and juvenile onset MS are both quite rare.

Currently the diagnosis of MS in children follows different criteria from that for adults since magnetic resonance imaging is more difficult to interpret in children and therefore information obtained is less certain than with adults. Based on this, a correct diagnosis requires the elimination, through testing, of many other types of diseases and disorders with symptoms similar to MS.

An important study, which began in 1989 in Göttingen, Germany, includes only children with symptoms beginning before 15 years of age, and has provided the MS community with important information on childhood MS. The study identified two types of childhood MS:

- Children in whom the disease started before puberty (10 years); this is classified as true childhood MS
- Juvenile MS (onset between 10 and 15 years of age)

Study results

Amongst the children with early symptoms before puberty, boys and girls are equally affected. Amongst juvenile cases the female to male ratio becomes 2:1 as in adult MS. In 54 per



True childhood MS is quite rare.

cent of cases a single symptom was observed at the onset of MS. While in 46 per cent of cases multiple symptoms were noted.

There was no evidence for a definitive association between vaccination or any specific childhood disease and the development of MS. Interestingly, the study found that in more than half of the children a non-specific infection, usually of the upper respiratory tract, occurred before the beginning of the disease or a new relapse.

The future for children with MS

This ongoing study will continue to provide new information. Although we are certain that

MS IN CHILDHOOD - WHAT THE MS MOVEMENT NEEDS TO DO

- Educate both the general public and medical profession
- Provide medical treatment and social support according to age
- Promote research

Remember: children are not small adults. There are great differences in needs amongst people with MS according to their age.

childhood MS does exist, there are still many questions remaining to be answered by research. Meanwhile, an early and correct diagnosis is very important for every patient. In children it carries far-reaching implications for their futures.

The important issues that accompany the diagnosis of MS in childhood for the child and family include:

- understanding the nature of the disease
- coping with disabilities, both potential and real
- schooling and education
- choices for professional life
- partnership and family planning

It is also important that healthcare professionals should educate parents of children with MS about vaccination and immunisation. Several MS specialists have suggested that:

- immunisation should be postponed during an acute episode or attack
- live vaccines should not be administered to

children receiving steroids or immunosuppressive treatment

- an interval of at least three months is recommended before administering vaccination or immunisation after immunosuppressive therapy
- children should receive immunoglobulins after exposure to measles or chicken pox or other highly infective agents if they have not been protected by prior immunisation
- oral poliomyelitis vaccine should not be given to siblings or others in the household during immunosuppressive therapy

Other information and recommendations on vaccination and immunisation can be obtained from an MS specialist or national MS Society.

The number of early, well-documented cases with true childhood MS is still very small and only time will tell how their disease will develop during adult life. Ongoing information and support is vital for the child with MS and for the family.

KIDS GET MS TOO: A GUIDE FOR PARENTS WHOSE CHILD OR TEENAGER HAS MS

The MS Society of Canada and National MS Society USA have teamed together to provide a unique support system for families who have a child or teenager diagnosed with MS. The network provides:

1. educational programmes
2. referral systems providing information from local MS society chapters
3. emotional support
4. family connections

If you want to learn more about this programme, contact childhoodms@nmss.org

Your questions answered

Readers of *MS in Focus* put questions to the Editor, Michele Messmer Uccelli.
With many thanks to our experts for their advice.

Q. I'm 37 years old and my husband, who has MS, is now very disabled. Being his sole carer is very demanding, particularly as he is unable to do any self-caring. I'm also trying to hold on to my job. Recently, a co-worker has been showing an interest in me, which has come as a pleasant surprise. I have never been unfaithful, but honestly it would be nice to have a sexual relationship with a healthy person who doesn't need anything from me. In trying to justify this temptation I tell myself that an extra-marital relationship might rejuvenate me and actually help me to be a better wife and carer for my husband. I've read some chatroom conversations and find that some partners of severely disabled people are really opinionated on the topic of extra-marital relationships. The problem is that arguments on both sides are valid. I was wondering if there has been any research done in this area that may help me?
Thank you, Ann

A. Unfortunately no research exists that can predict what would happen to your relationship with your husband if you were to have an affair. We have heard from partners of people with MS that an affair was destructive and as a result, an already precarious relationship deteriorated beyond repair. In other cases partners report that an affair helped the well partner to maintain his or her care-giving commitment. We do know that this is not an uncommon dilemma for partner-carers. In her book *Surviving Your Spouse's Chronic Illness*, Chris McGonigle writes that "...the question to have an affair is intensely personal. Each person has a unique set of values and religious beliefs...so each must be the sole-decision maker..." Although the final decision is yours, it might be helpful to talk over your feelings and doubts with a skilled counsellor or psychotherapist. Reference: C. McGonigle. *Surviving Your Spouse's Chronic Illness*. Henry Holt and Company, Inc. 1999. New York.

Q. My 19-year-old daughter was recently diagnosed with MS. My husband thinks she should know but I'm afraid that the news would scare away her boyfriend, whom she plans on marrying. If our daughter doesn't have any visible symptoms why should we tell her and risk the chance that she might end up alone?
Sincerely, Assunta

A. It's very dangerous keeping this type of information from a person, even if she is your child. Since MS is an unpredictable disease, symptoms could occur at any time and could be more or less debilitating. Also, not being informed about MS precludes her from beginning drug therapy that could help slow the progression of the disease. Furthermore, living well with MS is all about being informed and making informed decisions. The sooner a person with MS has accurate information, the sooner she can begin the process of adaptation and coping. Your daughter doesn't have this possibility if she is kept in the dark about her diagnosis. It is likely that the time will come when she will have to be told the truth due to new or worsening symptoms. There is a strong possibility that she will resent not being told the truth from the beginning, which creates other serious problems for your parent-child relationship.

A psychologist knowledgeable about MS can help you consider these and other aspects related to your situation.

Note: The idea that a physician can communicate the diagnosis of MS to an adult patient's family, and abide by wishes not to inform the patient, is a very difficult cultural and legal issue. In some countries it would be unheard of and in others it seems to be more acceptable.

Thoughts from a remote island off Norway

From Vasskalven, Peter Anker and his family talk to Chloe Neild about family life with MS



Peter, tell us about your family

I live in Oslo, Norway, with my wife Hege and our daughter Elisabeth (17) who is at high school. We have two sons Carsten (24) and Erik (23) who are studying away from home, but join us for holidays. I am now retired and enjoy the free time it gives. However, it is quite evident to myself and the children that Hege carries the burden of support in our family.

Peter, when were you diagnosed with MS?

I had my first neurological incident in 1964, when I was 11. Then in 1975 I experienced double vision and was diagnosed with MS by the doctor, but they did not tell me. The ethic was to “protect” young people from such things. I was 22 at that time and feel I had a right to know.

Five years later, when I was married with small children and living in the US, the symptoms of MS became more apparent. When we were on a family holiday in Norway, I contacted the doctor who had dealt with my case in 1975 and asked for more details. They then said I had a “demyelinating” condition. Afterwards I went for a walk with Hege and we realised that things were more serious than we had previously thought. She told me “it doesn’t change anything”. I then went back to the US ahead of the family and found out as much as I could about MS. I felt very alone at this time.

Later, as we began to understand the seriousness of the illness, I remember Hege saying: “I am your wife and will always continue to be that, but I will never be your nurse”. When I have told medical personnel that, they all say “and that’s the way it should be”.

Over the years most of the symptoms from when I was a child have reappeared. I also have a number of new symptoms, and must use a wheelchair sometimes or crutches to walk.

Hege, how have you balanced work and caring for a family?

When the children were young I did not work, I was a full-time mum and enjoyed being so active in family life. As Peter’s MS progressed that job grew. However, now that the boys have left home I work at a Montessori school.

Hege, what was it like bringing up children with MS in the family?

The boys cannot remember that their dad was able to walk and do things without support. However, we have a video that shows Peter pushing them on the swing in the garden without support of a cane or crutches. Elisabeth has never seen such things, but she vividly remembers how she reacted when I first told her why her father had difficulties in participating in



many of her school activities. For many years I had to double up in terms of getting involved in school and sports activities. I wanted the children to be as unrestrained and as normally functioning as possible. I always felt that they should not have to sacrifice and miss out on things because of their father's illness.

Peter, how did you tell the children about your MS?

It was a story that came out little by little. We never sat down for a "talk", but answered questions as and when they came up. We had no specific programme to educate them about MS. They saw the difficulties and we worked out ways to get by together.

Carsten and Erik, how did your father's MS affect your childhood?

When we were at school, we were all keen cross country skiers. Mom was always the one driving to and from events and watching competitions. For a long time many of the other parents thought Mom was a single parent since Dad was not at these events.

Elisabeth, what happened when you were told about your dad's MS?

One day at school, soon after being told about my dad's MS, I quite suddenly burst into tears and cried for a long time. Nobody in my class could understand what was the matter, and I had to explain that I was sad because my dad was ill and that he would never get well. One day I learned that there was another girl in my class whose mother had MS. We formed a club where we tried to gather as much information as we could about MS. It really helped to have someone I knew who I could talk to.

Carsten, Erik and Elisabeth, what do you think the future holds for your family?

We are all comfortable with Dad's condition now, and aware that it may get worse. Mom and Dad always try to say that the development so far has been extremely slow and will hopefully continue to be slow. We choose to be optimistic, but we all know that there are no guarantees.

Peter, tell us about your family's summers on the island Vasskalven.

Each year our family spends the summer at our house on the island Vasskalven, about 130 kms south of Oslo. It is a magical place, but has no regular electricity or running water and all transport is by boat. Reading light is produced by solar panels and drinking water is collected from a neighbouring island. I swim each day for exercise. The water temperature ranges from 18-22°C in the summer and it is quite remarkable for cooling my central nervous system – I never feel better than after a good swim in the Oslo fjord. We have built a hand bar system on the jetty so I can get in and out of the water on my own. However, getting into and out of a boat requires a bit of assistance from Hege or one of the children.

I can easily see that a more luxurious life would be easier for us all, but as long we're all willing to do what it takes, we're all happy spending summers at Vasskalven.

Peter, Hege, Carsten, Erik and Elisabeth, thank you for sharing your story with us.

MS Society of India reaches out to the community

By Sheela Chitnis, MA, CEO & National Co-ordinator, MS Society of India

Rationale

The MS Society of India (MSSI) organises free one-day medical camps for people with MS. This allows economically deprived people with MS and their families to see a variety of medical specialists in a sympathetic and accessible setting.

Objectives

- To make full check-ups by neurologists and other specialists freely available to the economically disadvantaged, and to people from remote areas who are otherwise deprived of medical expertise.
- To enable MS professionals to answer questions from family members – something that is seldom possible in busy and crowded clinics. Questions are invited before the camp and circulated to healthcare professionals to avoid repetition.
- To help to avoid stress and strain to people with MS who have mobility problems, yet normally must visit a variety of medical specialists at different times and places (which usually are inaccessible).
- To arrange for government authorities to issue disability certificates that entitle people with MS to special benefits including income tax rebate, travel concessions, etc.

Background

In India there is no financial help from government, nor public insurance for those who have MS. Medical consultation charges and treatment are beyond the reach of many. All too often, people with MS from deprived backgrounds bear their MS attacks silently, becoming more disabled without any support. Meanwhile, those who do visit the general hospital face long and distressing waits which can exacerbate fatigue and other MS symptoms.



People with MS meet the doctors.

Depending on their symptoms, people with MS need to visit a variety of specialists including: ophthalmologists, urologists, neuro-psychiatrists, general physicians, physiotherapists, occupational therapists and nurses. In addition, their families often have many queries for these experts. It became clear to MSSI that there was need for free medical camps, where check-ups, treatment, medicines, disability certificates and answers could be provided, and which would improve the quality of life for people with MS.

MSSI receives sponsorship and donations from pharmaceutical companies regularly.

Marketing the programme

Brochures and flyers are printed and distributed to all registered people with MS. Advertisements are placed in the local newspapers and on local radio networks. MSSI also displays brochures in general hospitals, pharmacies, railway stations and so on. This also helps raise public awareness of MS.

Programme structure

Prior to the camp, the MSSSI registers people with MS attending and takes a complete medical history. MSSSI keeps all files updated adding follow-up reports from physiotherapists, occupational therapists and specialists, as well as prescription details.

The camp lasts five to six hours. Separate booths, with necessary equipment and beds, are allotted to each doctor. The doctor receives a list of patients and free medicine is available. MSSSI also assigns volunteers to assist all healthcare professionals and attendees.

Physiotherapy and occupational therapy booths are busiest. Lots of attendees learn by watching exercise demonstrations given by senior therapists. These senior therapists work alongside MSSSI-employed juniors, who then regularly visit attendees at their homes.

A large area is provided to a team of government doctors who evaluate the medical papers of the people with MS and issue much needed disability certificates. These allow people to obtain several government benefits offered to physically challenged people.

There is a resting place for attendees where they can meet other people with MS. Wheelchairs and walkers are available to assist those with mobility difficulties.



Medicines being distributed to people with MS.

Outcome/Results

The first free medical camp was held in Mumbai (formerly Bombay) in 1998. Since then it has become a regular event and the most popular MSSSI project in Mumbai. Today nearly 200 attend the event, where over 25 senior doctors and their assistants give treatment and advice. The camp is also available in some other chapters of MSSSI.

An "extension programme" of the camp has introduced one-hour home physio/occupational therapy visits three times a week for 60-70 people with MS around Mumbai. Many receive this session free, whilst for others it is subsidised heavily.

Project costs

- Brochures, flyers, advertisements in newspapers and on local radio
- Venue with special booths and other equipment
- Transport for people with MS
- Food and drinks for all present (150 to 200)
- Photography
- Mementos for volunteers
- Stationery

Limitations

- Some doctors, due to emergencies, may not be able to attend the camp or need to leave early.
- When unexpectedly large numbers of MS families attend the camp it can overrun and cause confusion in agreed appointment schedules.
- If people are switched from their regular neurologist it can create awkward situations.

Suggestions

- Get sponsorship and allow sponsors to display their materials at the venue.
- Get publicity through the media.
- Involve as many neurologists and healthcare professionals as possible for free.
- Arrange for a large number of volunteers – their support is vital.
- Ensure venues are fully accessible, transport is straightforward and parking is available.

For further information contact MSSSI:
msindia1@vsnl.com

Reviews

Book review – *Life on Cripple Creek*

By Dean Kramer

Reviewed by Kathy Balt, Australia

I am an English-speaking Australian, who can also speak a little French. I can count to 10 in Dutch and in Italian, but I have no grasp at all of that very difficult language known as "medical jargon". Therefore, *Life On Cripple Creek* by Dean Kramer was a rather refreshing diversion from the infinitely more common, exasperatingly technical accounts of dealing with MS.

I chose to read *Life on Cripple Creek* while undergoing treatment for a MS relapse. I crave such books in order to understand how others cope with this disease.

I must admit I was a bit tentative about picking up the book because of its title. You shouldn't judge a book by its cover, but I did.

However, I overcame my nervousness and devoured the book. I laughed and I cried. I made dog-ears on many pages where Dean had articulated my exact feelings and thoughts. It was actually a wonderful journey through my own life.

I recommend this book to anyone who wants to understand what it is like to live with MS. It tells the truth, whilst also hitting the emotional mark. Don't be put off by the title, for this is a most enlightening and poignant story.

*Publishers: Demos Medical Publishing, USA, 2003. Price US \$19.95.
ISBN 1-888799-68-4
<http://www.demosmedpub.com>*

Book review – *Multiple Sclerosis: a guide for*

By Nancy J. Holland, T. Jock Murray, Stephen C. F.

*Reviewed by Melanie Trevethick,
New Zealand*

This excellent book begins by providing an introduction for those with little previous knowledge of MS. It describes the disorder in easy to comprehend language while assuming the reader wants more than a cursory overview of the subject. The various diagnostic processes are explained along with the symptoms most often experienced and their treatments.

Instead of falling into the trap of bombarding the reader with negativity, the middle section instead places great emphasis on how to maintain a positive attitude and live with the condition. It's a refreshing change. The book stresses the key to successful management of MS comes from acknowledging its presence in your life and according it a place where you can co-exist, side by side. It's the need to balance its symptoms within the framework of our lives, yet not become bound by a state of inertia because of them. This philosophy is best summed up in a quote on fatigue: "Stay active, with reasonable rest, not rest, with reasonable activity."

The difficulties of denial and grieving, and understanding in both an intellectual and emotional way the changes a diagnosis can bring, are handled in a sensitive yet challenging manner. More than merely stating these issues exist, the book offers valuable techniques to work through these phases and enhance

For the newly diagnosed

Reingold

the very relationships that sustain all our lives. It also provides sensible and practical advice on subjects such as employment, decisions on who and when to tell, and how to sift through the myths versus helpful advice available and circulating via the Internet.

The last section explains in more detail the current developments underway internationally to predict, identify and combat the effects of this complex condition. Current immunology research is described as pivotal to how autoimmune diseases are able to take hold; seeking to understand how and why immune system cells and antibodies cross the blood/brain barrier to enter the central nervous system. The new areas of genetics, glial cell, and infectious disease research also hold the clues that will eventually unravel the mysteries of this disease.

Overall, this is a book for the thinking person wanting a comprehensive and reasonably detailed view of where MS is at the present time. A very useful glossary and additional reading list completes it, delivering a must-have for anyone wanting answers and education about MS.

This book is available in English and Spanish.

Publishers: Demos Medical Publishing, USA, 2002. Price US \$21.95. ISBN 1-888799-60-9 <http://www.demosmedpub.com>

Website Review – The Well Spouse Foundation

By Marty Beilin, school teacher and caregiver, USA.

Founded in 1988, WSF is the only US national organisation dedicated solely to the support of spousal carers. Close to half of their members care for partners with MS. The organisation sponsors a network of local support groups – over 40 to date. The Well Spouse Foundation website (www.wellspouse.org) is one of the main ways the organisation keeps in touch with its members. The home page lists announcements and membership notices with links to pages containing more detailed information. Navigation is fairly easy with an index on each page. Information seems to be updated in a timely manner.

Of special note is the bulletin board section in the “Virtual Community”. Here, anyone can post a message. Many of the messages are quite poignant and reflect a wide range of emotions. This board is not moderated. When medical or legal advice is given, one has to be cautious since posters are essentially anonymous and one cannot ascertain their level of expertise.

The overall design and layout of the website is not sophisticated by today's standards, but many spousal carers and health care professionals will find a tour of the site worth their time and effort. Carers may gain new coping skills; professionals may gain fresh insights into the plight of the care-giver community.

The stress, anger, fear, sadness, and feelings of isolation that beset family carers finally began to overwhelm me six years after my wife was first diagnosed with MS. My family and co-workers were sympathetic, but more than anything they wanted me to reassure them that everything was “okay”. It was only when I met others in my situation that I could get the emotional support I needed. I would recommend the Well Spouse Foundation website to carers worldwide.

www.wellspouse.org

MS *in focus*



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MSIF is a non-profit charitable organization 501(c)(3) IRC chartered in the State of Delaware, USA, in 1967

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With many thanks

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International MS Nurse Care Plan

The new International MS Nurse Care Plan encourages the standardisation of MS nursing worldwide and promotes the MS nurse as a specialist in the field.

Based on previous work of the Canadian MS Nurse Network, European Nurse Network, UK MS Specialist Nursing Group, the plan was developed during an international meeting of nurses in September 2003 where, in the words of Coleen Harris (University of Calgary), "the most universal and significant theme was the significant role of the nurse in ongoing care of individuals affected by MS".

With multiple applications, the International MS Nurse Care Plan provides a comprehensive and practical guide to

MS nursing which may be used as a:

1. complete teaching and learning tool for MS nurse training;
2. professional development instrument for recognising MS nurse qualifications; and an
3. every day reference for practicing MS nurses

National experts are now encouraged to adapt the care plan to ensure effected implementation in individual countries.

The Care Plan was developed according to accredited continuing medical education regulations (CME). Content is free from commercial bias.

Maria Grazia Cali

President, Serono Symposia International
www.seronosymposia.org