

# The Energy Crisis:

by Renee F. Lyons

*Les problèmes de santé qui empêchent une personne de fonctionner normalement résultent souvent en isolement social et en solitude en un temps où la personne aurait le plus besoin de relations positives avec autrui. L'auteure explique qu'il ne faut pas minimiser l'impact d'un handicap sur la performance des rôles sociaux qu'une personne doit remplir et c'est pourquoi il est important de comprendre ce que la vie de chaque jour représente pour une personne handicapée. Dans ce contexte, les thérapies de groupe peuvent s'avérer très utiles pour partager le genre d'information qui va plus loin qu'une investigation superficielle de la maladie ou du handicap.*

There is a compelling need to utilize research on personal relationships to improve the quality of social life for people with chronic illness, and their close associates. Social science has traditionally reduced and segmented issues of illness and disability into tidy questions to be systematically investigated and theorized upon. However, in real life situations where people are confronting the challenges of preserving their identity and their social roles (being a parent, a son or daughter, a mate, a friend, a neighbour, a workmate, etc.), these themes must be pieced together into an understandable whole.

To study the issue of social adjustment and disability we selected mothers with multiple sclerosis (MS) because its onset is often in early adulthood, during the same time when parenting often occupies a central place in one's everyday life. Between 14 and 18 per cent of women in Canada (under 65) have a disability (Statistics Canada). Having Mom "get sick," particularly when that sickness is a chronic illness, can present a major crisis and disruption in families, where women are

increasingly assuming both paid work and caregiving roles. Although there has been considerable research on parents of children with a disabling condition, there has been very little work on the experience of mothers with disabilities (Thorne); and in particular, the impact on their social relationships.

Eight mothers participated in a series of three focus group sessions. They were between the ages of 26 and 40 and all had

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children between the ages of 2 and 16. Seven of the women were married and one was divorced and had been living with the same partner for the past five years. Although the presentation of symptoms varied in duration and severity, all had experienced the following as a result of MS: visual difficulties, numbness, weakness, balance problems, shaking of hands, and sensitivity to hot and cold temperatures.

They were asked questions on their background (general socio-demographics, family information); the onset of MS and diagnosis; the effects of MS on everyday life; adjustments in work, leisure, and family routines; the social network and the importance of network members to wellbeing; and social support, companionship, and enjoyment, etc. The moderator of the group was trained in group

process and focus group facilitation. The location of the meetings was selected to be easily accessible to persons with mobility problems and funding was provided for transportation and child care.

The sessions were audio-taped and the data were transcribed and analyzed thematically (Morgan). The themes were verified by a second analyst. The sessions were approximately two hours in length and were followed up with individual interviews. Interpretations of the results will be discussed with the participants at a final focus group session.

All of the women had received their diagnosis at least two years after symptoms had begun and expressed relief that the diagnosis legitimized their symptoms.

*I was twenty years old and two months when I started getting it and they couldn't diagnose me until three years later. I was just a neurotic woman doing all those things to get attention...Take three valium a day and you'll feel fine.*

Four of the participants were married before the diagnosis and half after. Each had a different experience with onset, presentation of symptoms, and life circumstances, and although they did not see their conditions as "text book cases," they contained many similar characteristics, such as an unusual set of physical and cognitive symptoms and unpredictability of health status.

*It's funny, a really good friend of mine has MS and she's in her midforties... She's got a perfect name for MS—Mighty Strange Disease. It sure is. You don't know what's coming next. You know, one day you're fine, the next day you're in a wheelchair. Then when you're over the*

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and L. Darlene Meade

*attack, you're back like there's nothing wrong and then you're back to a cane and it's cycle, cycle, cycle...mighty strange.*

All agreed that their symptoms could be easily exacerbated by stress, over-exercising, and viruses. Often, during the discussions, solutions were provided to specific problems.

*My husband...is away a lot and I don't have anyone to help me out. My friends work. There's no one there, so it's just me. And of course, this time of the year it's so hard...the heat. I just feel like Quasimodo, dragging the right leg with me and, oh please, I want to go back inside, and trying to play with my two and a half year old...just let Mommy stay in the shade and you go ahead... It's hard.*

*What you should get is a swimming pool and put it out in the summertime and sit in it. The kids will think "great"...you'll stay cool.*

The women all agreed that MS produced significant lifestyle changes and, in the process of adjustment were trying to accommodate their everyday life to the condition without having it take over their lives. However, four of the women had left their jobs as a result of the MS and one was considering taking a leave because of a recent exacerbation of symptoms.

*I have the job of my dreams...the one job I really wanted. And there are times when I find that really hard to come to grips with. I spent a lot of time getting into the position I'm in. And it combines so well with my family life.*

Another woman working outside the home was divorced and needed the money to support herself and her daughter.

*The trouble is I have to work. If I don't work, if I'm on disability, I lose my house. R. [her mate] makes \$20,000 a year and we'd live below the poverty line. So, I also have the financial pressure. If I'm not working, we don't really eat that well.*

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With respect to work roles, illness exposed and exacerbated the salient issue of inequality in work roles between men and women.

*...Even if the wife is healthy, the men don't do the housework, they don't contribute as much. It's still the woman that's doing everything. They're the ones that have to go out and work and come home and cater to, you know, try to be there for everybody else. And I know, my husband said something to me one day this year that took all the guilt off me. We said we'd like to have more money. And he said he didn't want to work two jobs and I said: 'Fine, I don't want to work two jobs, either, but that's what women are doing.' It's*

*hard on healthy women and it's even harder for people with health problems.*

To demonstrate the extent to which changes occurred in everyday life, the participants discussed changes in grooming procedures and the mixed message that a changed appearance might give to others about one's state of health.

*Another thing...that has changed is my appearance. The way that I dress...some fads that come out like shoes. Well you have to, I know myself and I notice other people, I've been checking underneath the table...flat shoes!*

*And just like our clothes. We go and instead of messing around with those little, little, tiny buttons where you're all thumbs—pull on stuff. Something easy to get on and get it off. And another thing—jewellery...the neck pieces. I can't get the clasp done.*

*...And another thing—hairdo's. Like we can't go and sit there with a curling iron, not anymore. You'd burn your scalp half to death and your fingers.*

*Yeah, and forget about putting makeup on. Try to put on mascara and you get it in the eyeball.*

*The worst part I find in terms of relating to other people is the worse I am, the more I've been resting, the more careful I am to put on my lipstick. So the worse I am, the better I look. So I finally explained to my boss: 'When I look good, like everything I have on matches, like I got my lipstick on straight, this is a very*

*serious sign. You have to understand this means things are bloody awful when I have it all together by a quarter to eight in the morning.'*

As a whole, this group of women perceived that they were coping reasonably well with the condition. Coping was linked to the ability to see value and meaning in life with a reduced range of lifestyle options, the ability to find solutions to day to day stresses, and the love, support and companionship provided by husbands/partners, their extended family, and friends.

All participants felt that MS had exerted significant changes in their social relationships. Energy was seen as a scarce resource preserved primarily for child care, work, and home maintenance, next for husband and family activities, and lastly, for friends. The concentration was primarily on children, on being a good mother.

*I've been hospitalized several times since I've been married. I've lost my vision and the ability to walk. Two months after my daughter was born, I had it really bad and I was concerned that I wasn't going to be able to look after her... and that, that bothered me.*

Personal leisure with family and friends was perceived as an infrequent experience. There was a tendency to avoid social activities involving physical exertion, and social situations where the symptoms might prove embarrassing or when the condition would have to be explained, such as large social gatherings with strangers.

*When you think you're going to have your speech slur or not say what you want to, you withdraw and you don't want to go places and meet new people.*

*...And you're always scared you're going to do something like your leg is going to give out or you're going to shake and people are going to question you and it's like, oh no, I have to go through this all over again!*

*I found that I didn't bother going to eat at restaurants because of my hand*

***"I was tired of watching everybody help out in the shop. I am not helpless. You may not think it, but I can do something."***

*tremors, because people used to stare at me. Here I was shaking, trying to get the food to my mouth. I used to say to my sister, loud enough for them to hear: 'Jeez, I should have had my fix this morning' and they wouldn't bother looking at me anymore...*

The arrangements for travel to see family and friends, and especially having to bring children to a house where they would have to be extra careful, were seen as exhausting procedures and hardly enjoyable in many cases. Preparation for such engagements would require energy conservation, followed by rest after the event. Therefore, there had to be a careful selection of friendship activities.

*Sometimes when I visit people...people that you know really well, you don't like to, but when you know that you're really tired, you ask if you could lie down for a few minutes. I close my eyes for a few minutes just to get my system back. It only takes a few minutes and then you're back to normal. And it's embarrassing. It's usually someone you know well and they don't care.*

This energy problem meant having to choose between obligations and leisure, a type of "work ethic" approach to relationships:

*When you're working, you've got people at work. But when you're home alone, you're cut off. So you need contact with people. And maybe you do something on the weekend and*

*your house doesn't get touched from Friday to Sunday. You say to yourself that you should be doing the housework and cooking. But then you need to get out in the normal environment. You're out seeing people and doing something enjoyable...*

As well, there was the issue of being at home when others are working and the resultant loneliness:

*Well, I find the area that I'm living in now, it's that the people are very...they work. Like, they all work ... the husband, the wife, they work and (sighs) and if the children were old enough, they'd probably work too. Like, I'm at home all day so it makes it difficult at times because there's not really somebody that you can just sit down with or see outside in the yard and say 'hi' to.*

An interesting, potentially useful taxonomy of support and companionship needs did arise. Instrumental support, for instance, was perceived as much more than the provision of finances and material aid, but often tied to enhancing leisure. For instance, a husband could be particularly helpful with children and housework on days when an evening social event was to occur, to preserve energy. He could supply "mom" with equipment and tools for pursuing a favorite leisure activity at home. Friends could take the children to organized recreational activities. Family members could reduce turmoil in the house by not having major projects, such as renovations, consume energy that might be devoted to getting the regular tasks completed.

*My mother would take the kids for one or two nights on the weekend so that I could sleep in and my husband [and I] had some time together with both of us working and me so tired...which I appreciated immensely.*

Emotional well-being was increased by the presence of support which facilitated coping with the condition, but the central theme was acceptance: to be included as a valuable, productive, and competent person who could increase the quality of

others' lives and who was not a burden; also, to be perceived as someone you could still have fun with. The following accounts describe the importance of contact with friends, and feeling productive and useful:

*I think that really I didn't lose any friends out of it and I consider myself quite lucky because I can see why people...I have seen it happen in other cases where people have just been so overwhelmed they just backed away. I felt really fortunate. We'd only been in Nova Scotia just over a year and a half when this all happened to us. So many of our friends were hearing about this 1500 kilometres away. So that was really hard on them...but an amazing number of them, in fact, 42 of them came to see us that summer (laughs) and I have the grocery bills to prove it.*

*...I was so sick and tired of watching everybody, like all the family, helping out in the shop and I used to just go and stand there and watch every time. I would try to help out and they'd say: 'no, that's O.K., you need your rest.' So finally when...they were painting the outside of the shop, I took a paintbrush and a can of paint and I said to them: 'Look. I am not helpless. I am going to prove to you that I can do something. You may not think it, but I can do something! I am not a little baby.' I was so proud that I had painted a row of shingles. I said: 'I did that,' and it makes you feel good that you're not helpless, that you can do something.*

*I must say I have a very supportive husband. He won't limit me. He says: 'You're a smart enough person, you know what you can and cannot do. But let's not push it'...and he'll purposefully plan things that he'll know won't stress me.*

Central to esteem support was reciprocity—being able to have opportunities to provide help to others in difficult times. This included emotional support to help significant others cope with the MS, such as discussing the diagnosis and symptoms with friends, family, and children.

***“Everybody's got something. Don't pity me. I don't want sympathy, empathy sometimes, but not sympathy.”***

*I phoned up my close family and my close friends and thought I may as well do this all at once. So I sat down with Mother Bell just loving it. I did all the phone calls at once, just one after the other. 'The good news is I don't have a brain tumor. The bad news is, I have MS. We'll cope with this. You know, in a couple of weeks, two weeks from now, we'll cope with this.'*

*And I think by giving the people closest to us this two week hiatus...then they don't feel obliged to say too much right away. And a number of them did say... 'I just don't know what to say to you.' Don't say anything. It's a bitch...but better than a brain tumor.'*

*...I just say to my father: 'Don't be sad. I'm not. You know. Everybody's got something. Don't pity me. I don't want sympathy, empathy, sometimes, but not sympathy.'*

*...[Children] seem to know more than you think. Mine's only two and a half...As I was lying on the couch...he looked at me and he came over and said 'Mommy tired? Mommy tired?' I said, 'Mommy's tired. Close your eyes.' And he crawled up next to me and laid down with me and he gave me a kiss and said: 'I love you Mommy' .... They really know.*

These are some examples abstracted from the 400 transcribed pages of focus group discussion. The focus group method

has many benefits. It allows women to present their opinions, provides an opportunity for the group to validate or critique points of view from their experience, and offers support and solutions. As the group continued to meet, it was obvious that the comfort in discussing personal relationship issues increased. Topics that caused discomfort could be saved for individual interviews. Telephone calls to arrange meetings were also fertile ground for reflecting upon focus group discussions. Several of the participants made special telephone calls to the MS clinic to thank the co-ordinator for inviting them to be involved with the group. Although the focus group method was not intended to produce generalizations about the social experiences of others with MS or others with chronic illness, it can complement and extend our knowledge of relationships and illness, and provide a basis for further studies which go beyond superficial investigations of the issues. For instance, one thing we are currently pursuing as a result of this study is communal coping orientation, the tendency to identify illness in close relationships as “our problem” versus “my problem,” and the tendency by women, in particular, to attend to the distress of significant others when they become ill.

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