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**#1 Fall 2003**

**Communicating Outside of the “MS-Box”  
with Health Care Professionals**  
by Kim Nolan & Dr. Ellen Ryan

“You have Multiple Sclerosis”. Most of us reading this article have heard these words. Do you remember the first time you heard them?

When Mr. F. was diagnosed, his physician threw a book about the disease to him and advised him to read it. After reading it, he was devastated. The book painted a desperate, pitiful existence for people. Ms. D. had a similar experience. Upon diagnosis, her physician told her that she had better enjoy her life now, with no further explanation. What did he mean? How was she supposed to feel? Research into MS shows many examples of inappropriate communication from health care professionals.

To those of us living with MS, those words will have different meanings depending upon how they are communicated to us. Often, people with MS are categorized into a box, based upon the existing stereotypes about the disease, which overlooks individuality. In order to understand communication encounters that people with MS experience in everyday life, a research project involving 24 MS Society members was conducted under the supervision of Ellen Ryan at McMaster University. We will present a series of articles over the next 4 editions of “Connections” to provide some insight and coping strategies for managing some commonly experiences of dissatisfying communication.

Living with MS means that we find ourselves in situations where we have a great deal of interaction with health care professionals including doctors, nurses, OT’s, PT’s, and chiropractors. It would be understandable to expect professionals to be empathetic of our disability and communicate effectively with us. Our data demonstrates otherwise. Participants reported more dissatisfying than satisfying communication encounters with health care professionals. In speaking about these encounters, many interview participants commonly voiced feelings of frustration and helplessness to a point where they were embarrassed to admit they had MS. Participants frequently reported feeling patronized because of MS. Is it possible to experience similar encounters without feeling discouraged or devalued? After diagnosis, many health care providers speak to us in certain ways because of our MS. Is it possible to communicate outside of the MS-box?

We have developed the **Communication Predicament of Disability Model**, which offers a way to communicate outside of that “box”. This model suggests that negative communication experiences of people with disabilities are based upon existing stereotypes of dependency and incompetence. Repeated exposure to such encounters may cause people with disabilities to conform to the stereotypes. As a result, people may respond passively or develop an aggressive stance, which leads to unsatisfying communication, a loss of self-esteem, and inadequate health care. The model proposes that it is possible to interrupt this negative cycle by using selective assertiveness.

Selective assertiveness refers to choosing to use straightforward communication about one’s wishes in order to meet one’s goals. It is characterized by a calm voice and relaxed

gestures. In using selective assertiveness, people with disabilities may communicate their needs through clear messages and gain high self-esteem and respect.

For example, we might explain to physicians that a companion may accompany us on medical visits as another set of ears, during times of fatigue. The presence of two people will ensure that complicated medical information is accurately received and all questions are asked. During the visit, we must make sure that physicians and companions are aware that we are in charge. We may also request that physicians provide instructions in writing to be reviewed at another time. Rather than allowing health care professionals to transfer us from our wheelchairs in their own way, we may use selective assertiveness to inform them of our individual transferring needs. Repeated use of selective assertiveness may eventually dispel stereotypes and result in more positive, satisfying communication. People with MS can become educators about their disease and in turn show health care professionals that it is possible to communicate outside of the MS-box.

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*2<sup>nd</sup> in a series of articles emerging from a McMaster study with MS Society members*

**#2 2003**

**Communicating Outside of the “MS-Box”**

*... about Mobility Devices*

by Kim Nolan & Dr. Ellen Ryan

Making the decision to use a mobility device is often difficult. Many of us resist giving in to a cane as long as possible. Life within the “MS-box” means that people with MS and without, expect that this move is inevitable. We all have memorable experiences about the first time we had difficulties walking. Ms. W. remembers walking down the street one day when her legs gave out and she landed on the sidewalk. A passer-by commented to her “Drunks like you should not be out this early in the morning”. That is when she decided to start using a cane. Ms. P has also been accused of being drunk and thought that using a cane would prevent other people from making assumptions. Although Ms. D does not like how she looks using a walker, she feels that using it allows her to be more independent.

If the time comes that we need assistance, there are a number of choices to be made. Using a mobility device can be a life-altering experience, whether we choose a cane, walker, wheelchair or scooter temporarily for balance and fatigue or permanently for functional decline. We choose a device in our own good time, with our own reasons. Ms. P thinks that each mobility device has a specific use, with different levels of stigma. Ms. P. says she tends to choose whichever device has the least amount of stigma for a given situation.

Use of a mobility device can influence the way people communicate with us. Ms. C believes that when using her walker in public, people do not want to talk to her. People who do speak to her either make the conversation about the walker or look at the walker before looking at her. Ms. B reports that when using her wheelchair, people treat her like a child by using a different tone of voice and manner. Many of the 24 research participants have had similar experiences, which make them more conscious of others’ negative perceptions. These perceptions are based upon existing stereotypes about mobility devices, including dependency, incompetence and helplessness.

The existence of these negative perceptions supports our communication model. Recall from the first article in the series that the use of our “Communication Predicament Model of Disability” offers a way to communicate outside of the “MS-Box” with health care professionals. The model may also be applied to communication about mobility devices. When using his cane, Mr. B has often noticed the frustrations of his companions because he has difficulty keeping pace. He opted for a passive response and he now limits his outings. Ms. M often finds she needs to be aggressive when her companions cannot tolerate the look of her mobility devices. Both types of responses may perpetuate stereotypes. The outcome is usually dissatisfying communication encounters, loss of self-esteem and possible isolation.

Often, we feel the need to apologize for our disability because we move more slowly or awkwardly, or our mobility device is in someone’s way. Using an elevator, attending a dance in a wheelchair or passing someone in a narrow hall are examples reported by our participants that may cause us to feel the need to apologize. Rather than apologize, we can opt for selective assertiveness to let people know that they must slow down or make more room for us. For example, Ms. S uses her decorated canes as a fashion accessory, which become comfortable conversation pieces. Ms. N uses humour by cautioning people about her poor driving skills when using her scooter. Often, stereotypes arise from a lack of knowledge. By using selective assertiveness we may raise public awareness about the need for our, and usefulness of, mobility devices in giving us independence. A new independent identity may reduce some of the stigma that exists in the “MS-Box”, which may reduce any stress, that is felt by people with MS who must choose a mobility device.

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*3<sup>rd</sup> in a series of articles emerging from a McMaster study with MS Society Members*

### **#3 2004**

#### **Communicating Outside of the “MS-Box”**

##### ***... about accepting unwanted help***

by Kim Nolan & Dr. Ellen Ryan

Living with Multiple Sclerosis means having difficulties with everyday tasks that most people take for granted. Activities such as getting in and out of bed, combing your hair, getting a glass of water, opening a jar, or carrying a basket of laundry can become overwhelming during times of fatigue. Even though completion of these tasks may be difficult, most of us are able to adapt or ask for assistance when necessary.

Within the “MS-Box”, our actions are often misinterpreted as struggles. In reality, we are merely completing a task in our own way. When someone is perceived to need assistance, people instinctively want to help. During one interview, Ms. L. stated that she is happy to accept help because she believes that living with MS sometimes means accepting help when it is offered.

Sometimes the help creates frustration for people with MS. Receiving unwanted help may make us feel like we are being watched and judged or incompetent. Mr. F. said he believes that people automatically think that they need to help him, but wonders who they are really helping. He does not like being helped because it makes him feel like a child and takes away his independence.

When people help without asking, he feels insulted because no one gives him credit for working hard to overcome his challenges. As an adult, he feels that a decision to accept help should be his.

It is easy to see how people may become confused when it appears to them that we may need help or are offended when their help is refused. If our polite refusals are not heard, our frustration may result in aggressive reactions. Mr. N. experienced this when he was wheeling himself up a steep ramp, which posed him no difficulty. The slow pace of Mr. N's progress was unacceptable to his friend, who started to push the chair. Mr. N. politely expressed his thanks and stated to his friend that he preferred the exercise. When the friend continued to push the chair, Mr. N. was forced to slam on the brakes. His friend was bothered by the incident, which essentially damaged the friendship.

Generally, MS Society members found acceptance of unwanted help to be a sensitive issue. They understand how people can be easily confused about offering help to someone with MS. How can we tell individuals with good intentions that we do not need their assistance? The negative stereotypes of helplessness and incompetence that exist about MS compel people to offer assistance. Recall from previous articles that, when communicating about mobility devices and with health care professionals, the application of our "Communication Predicament Model of Disability" can offer alternatives of communication. The same principles can be used to communicate outside of the "MS-box" about accepting unwanted help. If we state our wishes about accepting help at the outset, confusion may be avoided. Ms. B. states that if someone offers to do something that she wants to do herself, she will tell the person she would rather try herself first then ask for help if she needs. Mr. N. states that he is appreciative of the help offered because he knows that people just want to be helpful. He tells the person offering that the best way to help is by letting him do the task himself. Using selective assertiveness in such situations may reduce uncertainty and result in improved communication.

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*Final in a series of articles emerging from a McMaster study with MS Society members.*

**#4 Spring 2004**  
**Communicating Outside of the "MS-Box"**  
*... in the church*

by Kim Nolan & Dr. Ellen Ryan

People with Multiple Sclerosis may feel excluded from society due to lack of accessibility. It is often assumed that life within the "MS-Box" means that people living with this disease need to abandon many important life activities. Lack of privacy and reliance on others become commonplace. Think of the many activities of daily living that you have had to alter or eliminate. Your exercise patterns may have changed from jogging to yoga. Instead of jumping in your car and driving to the grocery store you may use public transit, ask for someone's help or have your groceries delivered. House cleaning may now depend on cleaning professionals, relatives or homemaking services. Taking a turn in your child's school trips or parent car pool may no longer be possible. Whatever changes need to be made, alternative solutions are usually

available that enable us to maintain self-respect, but the onus is on us to make the appropriate changes.

The one aspect of life where we would expect to find total acceptance and inclusion is the church. The church should be a place where people can escape the pre-determined expectations we encounter in society. People who enjoy a spiritual or religious component in their life find comfort in the church through interpersonal relationships. Many of our interview participants believe that church attendance is vital to their well being. Ms. S states that her religious beliefs are part of who she is and her strong faith gives her a sense of security.

Upon researching whether regular religious practices can be maintained in spite of disability, we found that communication in the church is often similar to other social situations. In previous articles we explored communication with health care professionals, about our mobility devices and about accepting unwanted help. We showed how by choosing to practice selective assertiveness, our “Communication Predicament of Disability model” could be a useful tool in maintaining a certain level of dignity when communicating with others. However, data from our MS Society interview participants shows that communication in the church may present us with new challenges. Barriers exist in theology, interpersonal relationships and matters concerning physical access.

Theological barriers for people with disabilities are an institutional aspect of biblical scriptures. Mr. N believes that although the Bible is a wonderful book, there are certain passages that relate sin to disability such as the healing stories in the New Testament. He believes that people may be left with the message that going to church and behaving according to the scripture means that disease would be healed. Realistically, he knows that this is not the way things work. Unfortunately, messages such as this are pervasive in the scriptures, which have resulted in negative stereotypes about disability. Because the scriptures hold ultimate authority in the church, members may develop paternalistic attitudes toward people with disabilities. Ms. F. states that although she believes she is doing well, people in the church show remorse for her and tend to think she is not doing well because she needs canes or a walker for mobility. On such occasions, she struggles to reconcile the attitudes with optimum physical functioning. Ms. W. feels that she is her church’s “pet project” because she is the only person who uses a wheelchair. Physical access in the church has been improving, but is still lacking due to financial restraints and paternalistic attitudes. Both Mr. N and Ms. F. have strong desires to participate in the church choir but are prevented by limited access for their mobility devices. Ms. S. and Mr. N. find that basement washrooms in the church impose major problems for people with MS.

People with disabilities could use selective assertiveness in beginning to dispel negative stereotypes of disability by advising church leaders and members that scriptural philosophies are reflective of past attitudes toward disability. When a church member insists on doing something for us that we can do for ourselves, we can suggest that they ask before helping but give thanks for their concern, thus reducing possible paternalism. Physical access is always dependent upon finances, but people with disabilities can use selective assertiveness to alert church leaders to the appropriate priorities of access. Eventually, communicating outside of the “MS-Box” will foster church inclusion for people with MS means much more than building a ramp to the church

doors.