

## What People With Newly Diagnosed MS (and Their Families and Friends) Need to Know

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### **Abstract**

*The aim of this retrospective study was to determine from people with multiple sclerosis (MS) and their families what information would assist a person with newly diagnosed MS — in which format, when, and from whom it should be delivered. Thirty-four Queensland, Australia, residents with MS and 18 family members and friends participated in the main study. Participants were self-selected for this purposive, statewide, cross-sectional study. Nine of the respondents answered open-ended questions in addition to the standard questionnaires, and seven respondents gave in-depth interviews.*

*The respondents recommended that people with a recent MS diagnosis and their families be given a wide range of information reflective of their personal needs. The information should be provided in person (in both group and individual sessions). They preferred to receive the information from their physicians and the staff of the Multiple Sclerosis Society. Research aimed at cures and therapies, as well as counseling and support services, should be discussed early in the course of the disease. Because of the small sample size and retrospective design, additional studies with larger populations are suggested to confirm these results and their cross-cultural applicability.*

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Knowledge is power, and people with newly diagnosed multiple sclerosis (MS) need accurate, timely, relevant information to take control of their health and lifestyle decisions. Lack of this knowledge further handicaps patients. We surveyed MS patients in Queensland, Australia—as well as their friends and families—about what information they felt was important to people with newly diagnosed MS, how they preferred receiving information, and when they wanted it.

People with MS need to make many long-term, information-based decisions about their illness, because MS is a chronic degenerative disease of the brain and spinal cord that generally strikes people between the ages of 20 and 50 years.<sup>1</sup> When people with a chronic disease recognize a specific gap in their knowledge or understanding, they seek information to help them make sense of their situation, solve a problem, or make informed decisions.<sup>2</sup> Their information-seeking behaviors represent an attempt to maintain some control over their lives, which is vital for people with long-term disability or illness.<sup>3</sup> This project began by searching out the available literature on the topic of informational needs.

As recently as 1994<sup>4</sup> and 1996,<sup>5</sup> the international literature discussing the informational needs and support of people with MS and their families was sparse.<sup>4,6</sup> A 1996 New Zealand study by Gregory and colleagues discovered that people with MS found generic information regarding MS readily available, but practical information at a local level was frequently difficult to obtain.<sup>5</sup>

The literature further stated that not only do people have various informational needs, but each person's response is likely to be either information-seeking or information-blocking.<sup>2</sup> The variation in information-blocking behaviors may be from fear of the unknown, fear of discovering distressing information<sup>2</sup>, or fear of frightening oneself.<sup>7</sup> Gulick<sup>6</sup> discovered that once many people with MS realized there was no known cause or cure for MS, they believed that more information could do little to alter their situation. As the disease progressed, however, they developed new informational needs in response either to new symptoms or to progressive deterioration of current symptoms.

People with MS continue to experience difficulties accessing information about practical day-to-day problems. The fragmented nature of community health services adds to the problem of obtaining information. Information about MS is becoming increasingly available through pamphlets, books, videos, and the Internet, however. What remains scant is research addressing the suitability and accessibility of the information provided—particularly in establishing whether it meets the needs of the recipients.

The goal of this retrospective study was to identify the most appropriate informational content for our targeted audience of people with newly diagnosed MS and their families and friends—as well as how (in what formats) and when the information should be delivered to help people decide on disease management strategies. To find out, we surveyed MS patients, as well as their families and friends. Participants in this project were asked to provide information based on their own experiences. While the project was retrospective, we felt that the outcomes would still provide important contemporary guidelines.

## **Methods**

The study design used a nonrandom, purposive sample, and the participants were self-selected. They were informed about the study through a variety of media (eg, community newspapers, the statewide newsletter [*People with Multiple Sclerosis Queensland—Forum*], and support groups for people with MS).

Eligible participants were 18 years or older, able to read and write English, and able to complete the questionnaire. Each participant gave written consent on his or her own behalf by completing the survey. Queensland University of Technology granted ethical approval.

## **Instrument Development**

Two survey instruments were developed specifically for this study; one for people with MS and another for their family members and friends. The People With MS Questionnaire included demographic data, items determining the length of time since diagnosis of MS, the level of disability at diagnosis, and usual support network. The survey was principally concerned with what type and format of information and services might have been most useful at the time of diagnosis. The questionnaire included items on the timing of the information as well as to whom, and by whom, information about MS should be offered. Other items addressed where and when information sessions took place. The Family and Friends of People With MS Questionnaire contained similar items, with the exception of the items identifying level of disability.

## Study Design

The study design was a statewide cross-sectional self-report. Before the main study began, a pilot study was performed with nine people with MS and eight family members or friends to establish the validity of the survey instruments. The respondents were made up of a purposive, nonrandom sample and reflected the characteristics of the people included in the main study. Respondents were asked about the general relevance of the questions and the pertinence of the questions to the participants. Suggestions were solicited from the respondents for other important issues not covered by the questionnaire.

Thirty-four people with MS and 18 family members or friends participated in the main study. All respondents were given the opportunity to add unstructured responses to four open-ended questions. The respondents were urged to "think back to when you [or your family member] were newly diagnosed" and respond to these prompt questions:

- The most helpful information I received was...
- I feel the information should be provided as (indicate format [eg, talk, book, pamphlet])...
- I think the best person to provide information is...
- The information about MS I would like to receive now is...

To attain a third level of response and add to the data from the structured surveys, the principal investigator interviewed seven people with MS and five family members. The in-depth interview sample was drawn from the main study. The option of being interviewed was given to all participants who were willing to be interviewed and who lived within a 90-minute drive of Brisbane. All participants who volunteered to be interviewed were included.

## Results

Twenty-three women and 11 men with MS participated in the main study (ages 38 to 81; average age, 54), reflecting the normal distribution of diagnosis of the disease (ages 15 to 50 years), which can occur from as early as three years or as late as the seventh decade (see Table 1).<sup>8</sup> The average time between first symptoms and diagnosis was 9.5 years; the mean time since the diagnosis of MS was 12 years (range, one to 38 years). Ten of the participants (29%) had MS diagnosed within five years of participating in this study (see Table 1). Fifty percent of the people with MS were not working because of their MS, and 20% were retired. Of the participants, only 14.7% were gainfully employed.

**Table 1.** Survey Participants.

	Pilot	Research
<b>AGE (y)</b>		
Mean	49	54
Range	34-72	38-81
<b>SEX</b>		
Men	2	11
Women	7	23
<b>YEARS SINCE DIAGNOSIS OF MS</b>		
0-5	2	10
6-10	3	10
More than 10	4	14
<b>HIGHEST LEVEL OF EDUCATION</b>		
Primary education	2	1
Some high school	4	12
Completed high school	0	7
Trade training	0	7
Tertiary education	3	7
<b>CURRENT EMPLOYMENT STATUS</b>		
Employed full-time	3	2
Employed part-time	0	3
Seeking employment	0	0
Homemaker	2	4
Student	0	0
Retired voluntarily	1	7
Not working due to MS	3	17

Eighteen relatives and friends of people with MS also participated in the research. Sixteen of them were between 40 and 69 years of age, and two children of a person with MS were 25 years of age or younger. Most of these participants (81%) were the spouse or partner of the person with MS.

### Quantitative Findings

The respondents to the "extent-of-disability questions" (found only in the People Newly Diagnosed With MS Questionnaire) self-described the study's MS population. They were permitted to check off more than one answer per question. When asked how disabled they were shortly after their own diagnosis, at least 50% of the participants recalled that MS had adversely affected their walking (79%), handwriting (65%), vision (46%), memory (53%), and mood changes (68%). Other answers (not listed) were given by fewer than 50% of the respondents. In addition, 38% of participants stated that their MS had resulted in the use of pads for urinary difficulties at the time of diagnosis.

People with MS and their family members and friends highly recommended that information on how one might be affected by MS should be given to patients with a new MS diagnosis (see Table 2). Information on managing and treating MS was also strongly recommended by both groups.

**Table 2.** Recommended Information for People With Newly Diagnosed MS and Their Families.

Recommended information*	Responses from people with MS		Responses from family members and friends	
	n = 34	%	n = 18	%
How MS may affect the person with MS	25	73	15	83
Managing MS	19	57	6†	35†
Treatment of MS	17	50	12	67

\*Response rate of 50% or greater.

†Response rate less than 50%.

The participants were also asked to identify the services about which they would have liked to have been informed at the time of diagnosis. The highest response rates from people with MS indicated that information about counseling, support groups, and exercises would have been about equally useful. The responses from the family members and friends were very similar (see Table 3).

**Table 3.** Recommended Information About Services.

Recommended information about services*	Responses from people with MS		Responses from family members and friends	
	n = 34	%	n = 18	%
Counseling services	21	62	11	61
People with MS support groups	20	59	12	67
MS Society of Queensland information services and library	23	58	12	67
Physiotherapy and home exercises	19	56	10	56

\*Response rate of 50% or greater.

People with MS (70%) and family members and friends (83%) agreed that the patient should be told of the diagnosis of MS. The two groups were in accord in telling their spouses or partners (82% and 67%, respectively). They also agreed about whom not to tell, with about the same difference in response level. People with MS would not give information about the diagnosis to their employers (68%) or to young children (80%). Similarly, 72% of family members and friends would not tell the employers or the younger and older children of the people with MS. Responses given by fewer than 50% of participants are not listed.

Fifty percent of people with MS identified the MS Society as a preferred source of information. In addition, people with MS felt information should be provided in the neurologists' consulting office (85%), followed by the general practitioner's consulting office (65%) and local MS support groups (59%). The local hospital, library, and their own homes were not recommended for information sessions. No consensus was achieved about the time of day or the day of the week these sessions should be conducted.

The survey also revealed that personal contact, whether in one-on-one sessions or in group information sessions, was the recommended format for receiving information about MS. Results from both questionnaires were consistent (see Table 4), except that family members and friends rated pamphlets as being a less important source of information. Forty-four percent of family members preferred videos as a format for receiving information. Respondents indicated that radio, telephone, television, scientific papers, and the Internet were not the preferred format for gaining information about MS.

**Table 4.** Recommended Format for Information.

Recommended format for information*	Responses from people with MS		Responses from family members and friends	
	n = 34	%	n = 18	%
One-on-one information sessions	23	68	9	50
Group information sessions	21	62	12	67
Pamphlets	19	56	5†	28†
Books	18	53	9	50

\*Response rate of 50% or greater.

†Response rate less than 50%.

### Qualitative Survey Responses

Of the 34 people with MS who participated in the research, five did not respond to the open-ended questions at the end of the survey instrument. One person responded to only one question, and another person responded to only two questions. The nonrespondents included five women and two men, all of whom were between 42 and 76 years of age. There was no identifiable characteristic that set the nonrespondents apart from those participants who answered the four open-ended questions in the survey instrument. Twenty-two people with MS answered the open-ended question focusing on helpful information. Seventeen percent of these people had been advised to contact the MS Society, 20% of them indicated they had received no useful information at diagnosis, and 10% had been advised to contact the MS Society at some later date. Responding to the same question, 30% of family members and friends indicated that they had been advised to contact the MS Society, and 20% stated that they had received no useful information at the time of diagnosis.

When asked to indicate a favored format of information, 24 people with MS responded. Thirty-five percent indicated that they would like an opportunity to talk with someone about MS, 16% suggested books, and 14% suggested pamphlets. Eleven of the family members or friends responded to the same question. Three (27%) preferred pamphlets, and two (18%) preferred videos, group discussions, and one-on-one discussions.

Twenty-four people with MS responded when asked if they wanted to receive any information now and what it should be. Forty-six percent would request information about research aimed

at a cure, 13% would seek treatment and medication advice, and 8% would want to receive information about the MS newsletter and the MS Society. Reflecting the views of people with MS, current information was requested by the 12 responding family members and friends who wanted information about research (58%), a cure (25%), and new therapies (25%).

### **Qualitative Interviews**

The principal investigator interviewed seven people with MS and five relatives and friends in depth. The interviews lasted 40 to 90 minutes and took place in the respondents' homes. The questions were posed to gain additional insights into their informational needs. They were similar to those in the open-ended questionnaires, as were most of the answers, which identified the themes for the analysis. The exception was the unexpected repeated responses about the strong impact of receiving information about MS. Family members also cited the stress associated with receiving this information. Many of the people with MS and their families and friends were shocked and dismayed by what they learned, but they still wanted to be informed.

Respondents with MS indicated that more information about MS and the usual course of the disease would be helpful soon after diagnosis. They felt it was necessary to inform people with a new diagnosis about what symptoms to expect. Family members and friends suggested discussing the impact of MS and why some people were more affected than others. They stressed the need for individualized information.

For sources of information, both groups looked to two specialist groups—physicians and the staff of the MS Society. People with MS also read pamphlets and brochures at the time of the diagnosis.

Face-to-face discussion was the dominant recommended information format for people with MS. The respondents welcomed the opportunity to participate in seminars for people with newly diagnosed MS, group sessions, and individual counseling for information. Family members and friends also recommended group sessions. Only one interviewee, a person with MS, mentioned using the Internet as an information source.

### **Discussion**

People with MS and their families want the opportunity to talk about issues pertinent to them. This research presents findings based on the views of people with MS and their friends and family members. While health professionals provide a range of information, this project set out to establish what consumers with MS want in the information they receive. Although only 34 people participated in this study, their characteristics reflect those of the population of people with MS. A larger project is needed to establish cross-cultural findings internationally.

### **Study Design**

A purposive sampling technique was used to ensure the sample reflected the characteristics of the population of people with MS. Purposive sampling—that is, the deliberate selection of participants—is appropriate where numbers may be limited and the researcher wishes to ensure a representative sample. The age range, sex distribution, and social characteristics of the research participants reflect the characteristics found among the population of people with MS. According to the responses of study participants, however, the symptoms associated with MS, such as fatigue, poor vision, and cognitive impairment, have a negative impact on the ability of people with MS to participate in research. Not included were those too disabled to respond and those not wishing to participate. The results cannot be generalized to include these groups.

Queensland is a huge state (656,370 square miles) with a population of approximately three million. Two thirds of Queenslanders live in the southeast corner of the state, in the greater Brisbane region and on the North and Sunshine Coasts. An estimated 4,000 people with MS live in Queensland, most of them in the Greater Brisbane region.

The use of the Internet in providing information is growing very rapidly. As previously stated, however, only one participant cited using the Internet for information soon after diagnosis. The characteristics of the research sample that may have an impact on Internet use may include limited education, reliance on social security benefits, and lack of experience with computers. This experience may also reflect the age of some of the participants.

## Results

This three-tiered research showed that people with MS and their relatives and friends believe that people with newly diagnosed MS will benefit from information about the disease. The results support the conclusion of Hileman and colleagues that providing accurate, relevant, and timely information soon after diagnosis of a serious disease (such as cancer or MS) to patients and their family members is an essential management strategy.<sup>9</sup>

This reflects the view of a shift in the information-seeking activities of people with MS and their families since 1994<sup>6</sup>—before the availability of the three disease-modifying therapies (interferon beta-1a, interferon beta-1b, and glatiramer acetate) for modifying relapsing-remitting MS. In the past, people with a diagnosis of MS made few attempts to obtain new information.<sup>6</sup> The recent success of the new therapies, and the hope they bring, has encouraged people with MS and their families to recommend dissemination of therapeutic information to people whose MS has just been diagnosed.

One issue raised by this research is whether the people with MS who wish they had had information at the time of diagnosis may, in fact, not have wanted to hear it at the time. This will always remain an issue. With most people exhibiting one of two broad styles of information gathering—information-seekers and information-blockers—there will always be some people wanting a great deal of information and others wanting very little. For health professionals, the difficulty is in knowing who wants what information—and when. What remains important is for people with MS and their families to know where and how to seek information—so that they can obtain it when they wish. If they know where to find the information, they can access it when they feel the need. While this may not overcome recollections of being poorly informed when information would have been most beneficial, it may prevent unnecessary delays in rectifying the situation.

All participants in our study suggested that more information about MS be made available to people with newly diagnosed MS. McMurray observed that, despite variation in information-seeking behaviors, individuals "will choose to take responsibility for their health."<sup>10</sup> The participants in the study universally agreed that specialists in MS (neurologists and MS Society staff) can provide that information and are the best source. This mirrors McMurray's belief that the information and options must be provided sensitively and in a way that will be readily understood.<sup>10</sup>

This research underlines that it is important for patients and families to be able to discuss MS with specialist health professionals—and the need for the professionals to individualize the information they provide. Our trial identified the urgent need for more information about the MS Society and its library, counseling, physiotherapy, and support services soon after an MS diagnosis. Not only does information help people make sense of their world and sustain hope, it also promotes self-determination. The promotion of independence and self-determination is the "greatest service possible to individuals with severe disabilities."<sup>11</sup> The ability to seek information helps people to solve problems and make informed decisions.<sup>2</sup>



People with MS and their families requested that more information be provided to the newly diagnosed and recommended that people with MS and their families have the opportunity to discuss MS. Even though generic information is readily available,<sup>5</sup> personal contact is needed for responding to individual information needs. Group information sessions and one-on-one sessions were requested repeatedly by the research participants.

At the time of MS diagnosis, people look for information about the disease and its social impact. Practical information becomes more important later on. Although not everyone with MS seeks information,<sup>2</sup> health professionals place themselves in a gatekeeping role by withholding the details of where information can be sought. This may not be in the best interests of the person with MS.

While the personal element of the health professional/consumer relationship may be the preferred option, access to it may present a formidable barrier. The practicalities of providing face-to-face education can limit its application. Even though neurologists provide some education during consultations, it is not usual for neurologists to run education sessions on an ongoing basis. In Australia, information is provided by general practitioners, MS societies, MS clinics, and information telephone services.

One finding of this research was that people with MS feel health professionals with specialized knowledge of MS are a preferred source of information. These people tend to be based in MS societies. MS societies and MS clinics may be the only source of ongoing face-to-face information about MS provided by MS specialists to people with the disease. The MS Society has established outreach workers in Queensland to provide information to people with MS living in rural and remote communities. Knowing where and how to find information is an important, well-recognized element in the provision of health care.<sup>12</sup> The respondents' preferred locations for information were the neurologists' consulting offices, their general practitioners' consulting offices, or the MS Society.

Although receiving information from physicians and MS Society members was the preferred choice, people with MS and their families need to be made aware of other sources of information. Despite their suitability to offer information about MS, the ability of neurologists and general practitioners to address day-to-day issues has been questioned over the past decade.<sup>13,14</sup> Physicians have been criticized for their lack of knowledge about the difficulties that people with MS experience in their daily living, as well as with their Social Security benefits or other entitlements.<sup>13,14</sup>

The respondents stated that the MS Society was able to provide such information, as were MS support groups. Of grave concern to us is that only 17% of the participants in our study were advised to seek out the MS Society at diagnosis. An additional 10% were advised to seek it out "at some later date." This left 73% of people with newly diagnosed MS on their own to find the information they needed! Since the provision of timely, accurate, and helpful information is empowering, withholding such information is tantamount to disabling!

The Internet is the most recently developed source of current information, but it does not provide the personal contact that these people with MS and their families feel is vital. Internet information spans a huge range of issues, including heart disease, physical training regimens,<sup>10</sup> and MS. It does have the potential to provide an enormous amount of information—but only to those with computer access, computer literacy, or the finances to achieve both.

It may be justifiably argued that this sample, with a mean age of 54, may not reflect the wealth, computer literacy, or Internet skills of younger people with MS. Younger people with MS, who may routinely use computers in their jobs and may have easy access to computers and good computer literacy, may well utilize the Internet much more extensively than the

sample group in this project. Hard data on Internet use among people with MS are very difficult to establish. Some estimate that 30% of the total MS population (and nearly everyone with a new diagnosis) uses the Internet for information about MS. The issue of access to a computer must be a consideration if education is to be provided via the Internet.

### **Conclusions**

The people with MS and the relatives and friends who participated in this research wish to be provided with a range of information reflective of their individual needs. They want the information provided in person, in both group and individual sessions. They need to identify appropriate, available therapies and receive counseling, support services, and information about research aimed at cures. These findings, while providing useful information for health professionals, were generated from a small sample group, and care must be taken before generalizing about other groups of people with MS. Further research is required to confirm these findings.

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