

# **The Information Needs of People with Multiple Sclerosis (MS)**

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## **Executive summary**

This research took place between January and October 2002. It was conducted by the Department of Information Science at Loughborough University and funded by the MS Trust.

### **Aims**

The aims of this study were to:

- ◆ comprehensively understand the information needs of people with MS;
- ◆ determine what information needs were most important to people with MS;
- ◆ determine what information was currently most difficult to find;
- ◆ specify what data, information and knowledge should be made available to people with MS;
- ◆ recommend how data, information and knowledge should be made available to people with MS.

The research has demonstrated there is considerable scope for improving provision of information to people with MS and that this would enhance their quality of life.

### **Methodology**

Qualitative and quantitative methods were used. Eleven focus groups involving 103 people with MS of differing severity took part. These were held in England, Wales and Scotland. Discussions were structured to ensure that specific situations affecting people with MS were explored.

This data, along with the published literature and input from stakeholders and the MS Trust, were used to inform the development of a questionnaire. The questionnaire was distributed to 4,100 people with MS through: the MS Trust, MS Society, therapy and respite centres, newspapers and the internet. 2030 questionnaires (49.5%) were returned.

### **General findings**

- Someone with MS should be seen as a person, and not only as a person with MS, who is likely to want to take an active role in life. Information should be provided that helps achieve this goal. Enabling people to participate actively in life whether in the home, workplace or elsewhere has a positive impact on their self-esteem and general well-being.
- Information provision at the time of diagnosis has improved. Before 1980 less than 20% of respondents received information at diagnosis compared to approximately 70% in 2000 and 2001. The consistency of information provision still needs to be improved. Information provision on specific topics is still very uneven and needs to be improved.
- Negative experiences of the diagnostic process (50%) were associated with 'a lack of support', 'little information', 'poor attitude'.

- At diagnosis over 50% of the respondents wanted information on managing symptoms, drug treatments, disease course, physical symptoms, exercise, diet and information for the family.
- Information provision to people who have been diagnosed within the last 5 years was generally consistent with that provided to the entire surveyed population. However, at diagnosis, information provision on drugs has increased in the last five years by 13% and information about MS nurses by 19%. This reflects the licensing of Beta Interferon and the increase in the number of MS nurses.
- The information needs of people with MS in general has remained consistent over time.
- People with MS generally welcome information. Not all people with MS, however, wanted the same information or wanted to be informed at all. Information provision therefore needs to be sensitive to the needs of the individual.
- The cognitive and physiological condition of the person with MS affected their information behaviour. For example fatigue, loss of concentration and limited mobility all had a negative impact on information behaviour. Information provision therefore needs to be sensitive to the cognitive and physiological condition of the person with MS.
- A distinction exists between information needs at diagnosis and long term information needs. Information providers need to distinguish between what may be needed at diagnosis and the information needs associated with MS over time.
- 65% of the respondents found it difficult to find out about drug treatments, research trials, balance problems, emotional changes, stress, new and unusual symptoms, and also about state benefits and entitlements.
- 40% of respondents felt that it was very important to have information on balance, walking problems, bowel and bladder disturbances, drug treatments and research.

### **Recommendations for information provision**

#### **Targeted information provision**

Information about MS and related issues should be made available to:

- **People with MS**
- **The general public** (including family and friends). This would include general information about MS and living with MS and the support available.
- **Service providers.** This would include general information about MS, the help and information that is available.

- Service providers, including health and social care professionals and support groups, should be trained in the information needs of people with MS and how these might be satisfied.
- Health professionals involved in diagnosis need to be trained to provide information at diagnosis and in a supportive and sensitive fashion.
- Service providers need to be aware of the variability of the condition and how the nature of MS may change over time, and that informed support is required over an extended period of time.

## **Information provision for people with MS**

### **The character of information provision**

Information should be provided:

- in a positive manner;
- in a way that helps and motivates people to take action;
- using the most effective means of communication; (this will vary depending on the nature of the information and the cognitive and physical condition of the person with MS. For example, face to face communication will be more appropriate for sensitive or complex issues.)
- that corresponds to condition of the person with MS
- in a way that is sensitive to the desire for information and its possible impact.

### **The content of information provision**

The following information should be provided to the person with MS (bearing in mind the need for the provider to take into account the situation of the individual).

At diagnosis people with MS generally should have access to information on:

- managing symptoms
- drug treatments
- the possible course of the MS condition
- physical symptoms
- information on exercise
- information for the family
- information on diet.

Thereafter categories of information need to fall under two headings: '**information about MS**' and '**information that helps the person with MS interact with the world around them**'.

### **Information about MS**

In general people with MS should be provided with information about:

- MS, a general explanation
- MS research trials

- drug treatments
- symptoms
- prognosis
- treatment and management of symptoms
- physiotherapy
- complementary therapy
- nutritional advice
- health and fitness
- emotional changes

### **Information that helps the person with MS interact with the world around them**

This would include information about:

- service providers (health service, social service, benefits agency, voluntary organisations)
- the services that providers give
- support groups
- aids and appliances
- facilities for the disabled
- MS and work and the issues associated with giving up work
- communicating about MS with family, friends, colleagues and the public
- leisure activities including, when necessary, provision for the disabled

### **Providing access to information**

- Information should be provided using the most appropriate medium. For example face-to-face, leaflets, booklets, newsletters, email, world wide web, video conferencing and chat rooms could all play a role in information provision and exchange.
- Information should be provided in different formats to cater to the individual needs of the person with MS. For example fatigue and problems with concentration would demand that information is provided in a succinct manner. Visual problems would also have an impact on information provision.
- Access should be provided to different types and sources of information for example professional articles, popular press, experts and other people with MS to satisfy the information seeking behaviour of the person with MS. Enabling access to other people with MS should be seen as a key role for any information provider.

### ***Further research***

Further research is recommended into:

- how the cognitive, physical and personal characteristics of the person with MS affect their demand for and use of information;
- the impact of information provision on the well-being of a person with MS.

## **Part 1: Introduction**

### ***Aims of this study***

The aims of this study were to:

- ◆ comprehensively understand the information needs of people with MS (PWMS);
- ◆ determine what information needs were most important to PWMS;
- ◆ determine what information was currently most difficult to find;
- ◆ specify what data, information and knowledge should be made available to PWMS;
- ◆ recommend how data, information and knowledge should be made available to PWMS.

### **An explanation of 'information needs'**

The concept 'information needs' was interpreted as follows:

- Data, information and knowledge that helps the PWMS cope with situations and can lead to more effective management of the condition and improved quality of life.
- Information needs are associated with immediate as well as long-term situations, for example: diagnosis; the onset of a new symptom; the need to acquire a mobility aid or a state benefit; dealing with incontinence or maintaining a positive state of mind.
- Information needs include both stated needs and those which may not be stated or are unrecognised by the individual.

### ***Overview of Multiple Sclerosis***

There are approximately 85,000 PWMS in the UK. MS affects more women than men (approximately 2 women for every 1 man) and is generally diagnosed between the ages of 20 and 40. In parts of Scotland it is estimated that 1 in 500 will have MS; for the rest of the UK it is approximately 1 in every 1000. A study by Williams et al. (1995) confirms this north/south gradation in prevalence. As a general rule MS becomes more prevalent with greater distance from the equator.

In MS the myelin sheath around the nerve cells is attacked, the nerves become demyelinated and may not function as they should. MS can affect any part of the central nervous system and can potentially alter movement and muscle activity at several different sites, giving rise to a variety of physical and psychological symptoms. Although it was first identified in the 1860s the cause(s) of MS remain in dispute and a cure is elusive.

### ***Literature review***

Little research has previously been conducted, specifically, on the information needs of people with MS. Earlier research tends to be general and does not attempt to identify comprehensively and categorise the information needs of

PWMS. It has been recognised, however, that PWMS need to make long-term, information-based decisions about their condition (Wollin et al 2000).

In 1996, in the UK, Robinson, Hunter and Neilson conducted a qualitative study of the needs of PWMS. Part of this study concerned information. They found that appropriate information was hard to find and use and that it was not available when and where they wished to access it. The information needs that were identified included:

- Information on the condition itself
- Symptoms and managing symptoms
- Current research
- Benefits and entitlements
- Insurance and mortgage advice
- Transport for the disabled
- Suitable holiday venues
- Respite care
- Medical and complementary therapies
- Social and support groups
- Voluntary organisations
- Employment and statutory rights advice
- Home adaptations and aids

The report highlighted that individuals might have different information needs at any particular time due to different circumstances. The report concluded that a centralised source of information would be useful.

In 1977 Matson and Brooks in the US studied PWMS to determine how they had adjusted to the condition since diagnosis. They concluded that most adjustment takes place in the first ten years after diagnosis. Based on their findings they proposed a four-stage model of adjustment to MS, in which information plays a role. Newly diagnosed patients entered stage 1 (denial) immediately. Here they sought information through different medical channels in an attempt to dispute the diagnosis. In stage 2 (resistance) it was shown that people acknowledged the possibility of having MS and anxiously sought information about the condition and a cure. Patients also turned to others with the same condition and participated in groups or classes to garner any information that might be helpful. Stage 3 involved telling other people about MS. Stage 4 began when a person had fully accepted the condition.

Matson and Brooks stated that information given by the consultant was seen as inadequate, perhaps because patients desired life-encompassing direction, which might be beyond the knowledge of the individual consultant. Most PWMS wanted practical information that would help them live with their condition. To find this information they used a variety of sources, with varying degrees of success.

Stewart and Sullivan (1982), in the US, found that information seeking activity starts in the pre-diagnosis period and continues until a diagnosis of MS is confirmed. They also found that, because symptoms could be fleeting and

might vary from one exacerbation (attack) to another, people engaged in 'physician shopping' until they found a doctor who could diagnose their condition. People also sought information from popular literature and medical texts, as well as from health professionals, family and friends. Brooks and Matson (1987) noted that in the post-diagnostic period, people with MS wanted practical information to help them live with their condition and sought information from other people with MS.

Baker (1997) in the US undertook a study of people who had recently undergone an acute exacerbation of MS. This study involved a questionnaire survey of 260 women. The results helped to identify categories of information need and contributed to the questionnaire design in the current study. Categories of information need included:

- physiological (general information about MS, nutritional literature, fatigue, bowel and bladder disturbances etc.);
- psychological (dealing with a hidden disability, emotional behaviour, spiritual material etc.);
- social (education, support for family members, branches for women etc.);
- economic (insurance, employer relations etc.).

Baker revealed gaps in people's knowledge about physical symptoms PWMS were experiencing, emotions they felt, and drugs that could be used. Various sources of and barriers to obtaining information were identified. The results also suggested that health professionals needed to be aware of the continuing need for relevant, current and specific information to help PWMS retain their independence and to enable them to make informed decisions.

Baker (1994) also found that people tended to fall into the category of either 'monitors' or 'blunters', that is, people 'either want information to handle an uncontrollable event or turn away from it because information is perceived to increase their level of anxiety'.

A New Zealand-based study by Gregory (1996) discovered that people with MS found generic information regarding MS readily available, but that practical information at a local level was frequently difficult to obtain.

In a recent review of health care preferences of people with MS in the UK, Somerset (2000) found that three quarters of the people surveyed reported lacking advice about at least one MS related issue and 17% lacked advice in five areas. The most frequently consulted health professional was the GP followed by the hospital consultant. The professional that most people said they would have liked to see, however, was a MS specialist nurse. The study concluded that people with MS displayed a wide variation in their unmet needs, and that information about MS management (both conventional and unconventional), relevant tailored advice and access to appropriately skilled professionals should be components of high quality care.

The literature does, therefore, provide some insight into the information needs of PWMS, their information seeking behaviour and information provision. The needs can be seen to be broad and PWMS might not be successful in

satisfying them. There is currently, however, insufficient detailed empirical data to enable a comprehensive definition of the information needs of PWMS.

## Part 2: Methodology

### Overview

Qualitative and quantitative methods were used to conduct this study. Following the literature review, a qualitative technique, the focus group, was used at the start of the project to help orientate the researchers to the experience of PWMS and to gather rich data on that experience and the role information played.

This was followed by a large-scale quantitative questionnaire survey of PWMS. The questionnaire design was informed by the qualitative findings as well as by the literature review, and valuable feedback from both the stakeholder group and the MS Trust. The objective of the questionnaire was to determine the demand, importance and accessibility of information amongst the wider population. It also provided an opportunity for PWMS to identify additional categories of information need that might have been overlooked by the researchers. The questionnaire was distributed through many channels to reach the widest possible audience of PWMS.

### Qualitative methodology

The focus groups enabled PWMS to identify situations of significance to them. The group discussion was structured using the micro-moment time-line technique (Dervin 1983). In this technique the researcher focuses on specific situations experienced by the respondents and explores how people move through these situations and the barriers and 'helps' that people experience. Particular attention is paid to how information can enable people to deal with these situations.

### Locations and participants

Eleven focus groups (including an initial pilot session at Leicester) were held in England, Wales and Scotland (see table 2). Sites were chosen to achieve as wide a geographic spread as possible and also because the venues (MS Therapy Centres) provided sufficient space as well as disabled access. Each focus group was attended by 7-12 PWMS and each was designed to involve people who had similar levels of disability.

Mobility	Number of Participants	Percentage
No walking aids used	61	59%
Wheelchair users	21	20%
Used walking stick(s) or walker	21	21%

**Table 1** *Mobility of focus group participants at the time of the focus group*

This compares with figures, on mobility, for the MS population as a whole where 51% require no walking aids, 20% walk with aids 20% and 29% are unable to walk (Compston et al. 1998).

Participants were self-selected and volunteered, having seen a poster in the MS Therapy Centre or were alerted to the focus group by the local MS Society branch.

Venue	Men	Women	Total
Bedford	3	8	11
Bristol	7	3	10
Dundee	3	4	7
Exeter	5	7	12
Glasgow	4	5	9
Leeds	3	9	12
Leicester	5	3	8
Middlesborough	0	10	10
Reading	3	5	8
Sussex	6	0	6
Swansea	3	7	10
<b>TOTAL</b>	42	61	103

**Table 2** *Location of focus groups and numbers and gender of participants*

### **Focus group structure**

At each focus group participants were given an information sheet (See Appendix 1) with details about the project and what would be happening in the focus group.

The researcher then asked participants to describe, on post-it notes, situations, either positive or negative that they had encountered since, and including, their diagnosis with MS. These were then collated and the most common situations (usually about four) identified by the researcher. These were then discussed by the group. The micro-time line interview technique was used to provide a structure to the discussion. This required the groups to talk about:

- ◆ the context of the situation;
- ◆ the people's knowledge or lack of knowledge about the situation;
- ◆ how they got information to help deal with the situation;
- ◆ the importance of the information;
- ◆ the completeness of the information available;
- ◆ how they used information to help deal with the situation;

- ◆ barriers and 'helps'
- ◆ specifically how information helped or hindered
- ◆ what information would have helped.

Generally the topics of most concern to the group were discussed. As the focus groups progressed, however, an effort was made to discuss new topics rather than go over old ground. The objective was therefore to get an understanding of the range of situations that PWMS experienced.

### **Focus group data analysis**

The focus groups were tape-recorded and these recordings were transcribed verbatim. A qualitative data analysis package, Atlas/ti, was subsequently used to code the data using the broad headings: situation, knowledge, artefact and artefact behaviour.

A brief explanation of these headings follows:

**Situation:** refers to situations that people experienced such as diagnosis, giving up work, finding out about benefits, talking to the family or children about their MS. The range of situations was summarised and categorised as either positive or negative.

**Knowledge:** refers to what people knew or needed to know about a given situation.

**Artefact:** refers to people, organisations and things that people interacted with while experiencing the situation. This included, for example, consultants, GP's, family members, voluntary organisations, the benefits agency as well as books, leaflets, the internet etc. Interaction with artefacts may or may not involve the exchange of information. Data on artefacts and artefact behaviour was categorised as either negative or positive.

**Artefact Behaviour:** refers to how the artefact behaved in relation to the person with MS. For example, whether they gave information, helped fill in a form or helped get equipment and how this took place.

Within these broad headings common themes were identified inductively, that is, not using predefined categories. This helped to ensure that the findings were grounded in the data.

### **Audio diary**

Five PWMS agreed to use a dictaphone to record their thoughts and feelings over the space of a month. This was largely an experiment to see whether data gathered using this technique would be different from that collected by the focus groups and questionnaire. It was felt that focus group sessions and questionnaires tended to concentrate on the more obvious issues whereas an audio diary could pick up on the smaller day to day experiences of the PWMS that might be overlooked. The data were transcribed and analysed.

### ***Quantitative methodology***

The questionnaire survey was conducted to obtain input from across the wider population of PWMS, and to determine the significance of defined categories of information needs as well as the opportunity for PWMS to identify any other categories of information need.

### **Design of the questionnaire**

The content of the questionnaire was informed by the literature review, the focus group discussions as well as by input from the MS Trust personnel and the project's stakeholder group. The questionnaire was piloted with a local MS therapy centre. For a copy of the questionnaire see Appendix 3.

The main topics covered in the questionnaire were:

- personal information (gender, age, employment, severity of MS)
- diagnosis (source, information given, information they would have liked)
- people or organisations PWMS use for information
- the difficulty of finding categories of information
- preferences for how different categories of information should be provided (leaflet, the internet etc.)
- the relative importance of different categories of information
- how sight, dexterity, mobility, memory, fatigue and concentration affect their information seeking behaviour

The questionnaire was designed in 14pt type to allow ease of reading. Tick boxes were generally used to answer questions. This enabled a large number of questions to be asked without imposing too much effort on the respondent. Two questions were asked which required a written response:

- an example of where information had made a positive difference to their lives and
- tips on living with MS for other PWMS.

The information sheet that accompanied the questionnaire can be seen in Appendix 4.

### **Distribution of the questionnaire**

Four thousand one hundred questionnaires were distributed via:

- MS Trust
  - the study was advertised in the MS Trust's newsletter
  - a list of two thousand people who had had contact with the MS Trust regarding MS were sent the questionnaire
  - a link was provided from the MS Trust's Web page to an electronic copy of the questionnaire
- MS Society
  - the study was advertised through the MS Society's news letter sent to all local MS branches

- MS therapy centres
- MS respite centres
- A magazine read by people with MS
- The Walton Centre, Liverpool
- MS discussion groups hosted on the Internet. A link, from the invitation to participate, was provided to an electronic copy of the questionnaire.
- An announcement in local newspapers

### **Response rate**

The response to the questionnaire was excellent. 4100 questionnaires were distributed. 2030 were returned giving a return rate of 49.51%. Of these 280 were completed by someone on behalf of the PWMS, for example, by a formal or informal carer or family member.

### **Analysis of the questionnaire**

The questionnaire responses were manually input into a Microsoft Excel spreadsheet. Data was then ported into the statistical data analysis software SPSS. Frequencies, modes and means were calculated and the data analysed for correlation and significance.

## Part 3: Findings

### ***Qualitative data analysis and findings***

It should be noted that qualitative data tends to be exploratory and assists with the understanding or identification of variables. It is often used, as in this study, to inform further quantitative research that will, in turn, help to test suggestions drawn from the qualitative research.

The qualitative data should not be evaluated from a quantitative perspective. Where qualitative data is quantified, for example, by using a table to present the data, quantification is used only as a possible indicator of the significance of the topic to PWMS.

Respondents who took part in the focus groups included both people who had been recently diagnosed and people who were diagnosed more than ten years ago. Table 3 shows the topics that were discussed in detail during the focus groups. For a complete list of situations that the respondents wrote on their post-it notes at the start of the focus group sessions, see Appendix 2.

<b>Topics discussed</b>
Access to an MS Nurse
Coming to terms with MS
Coping with symptoms
Depression
Diagnosis
Disabled parking
Disabled toilets, access and design
Driving
Family, children
Filling in forms
Finding out about benefits
Finding out about Blue Badge, Radar Key, etc
Finding out about drug treatments
Finding out about physiotherapy
Finding out about MS Therapy Centre
Finding out how to get equipment
Giving up work
GPs and consultants
Holidays
Lack of information on current research
Other people not knowing about MS
People's reactions to a wheelchair
Problems encountered on daily basis
Telling employers, friends, family
Treatment by NHS
Wheelchair access

**Table 3** *Topics discussed in detail during the focus groups*

## **Key themes identified in focus group data**

Having coded the transcripts of the focus groups, the data were analysed and key themes and topics were identified. The following text summarises these findings and discusses their implications for information provision. Quotations from the transcripts are included to help to understand the tone of the comments made by people in the focus groups and to illustrate how the themes and topics are grounded in the data.

### **Lack of knowledge**

Prior to diagnosis people who attended the focus groups knew very little about MS.

#### **“I knew nothing of MS, I knew nothing”**

They also knew very little about the health service, social services, the benefits agency or other agencies that could be of help or how to instigate help from these agencies.

#### **“... how much do you know about benefits and all that stuff? A lot now. And before? Nothing.”**

As soon as people were diagnosed they therefore had significant information needs with regard to the systems and services that they would probably need to deal with and use.

Positive descriptions of interactions with organisations, places and people tended to be either associated with receiving information or positive emotional support. This indicates that PWMS appreciate information provision and are therefore a good target community for information provision. The quantitative questionnaire data supports this view. A significant number of the questionnaire respondents, however, did not want apparently useful information such as managing symptoms or possible drug treatments to be provided at the time of diagnosis.

### ***Implications for information provision***

- ◆ potential information providers should recognise that generally people would like to be informed
- ◆ PWMS require information on a broad range of topics, including information about services as well as their individual condition
- ◆ information should be provided or made available in a way that is sensitive to individuals and their situation.

### **Diagnosis**

The most common problematic situation that was discussed in the focus groups was the diagnostic process itself. This was responsible for the greatest number of negative experiences amongst the people involved in the focus groups. Forty nine percent of the people attending the focus groups mentioned the negative experience they had when they were given their

diagnosis. Only eight people were happy with the way they were given their diagnosis. People were clearly unhappy with consultants and GPs who were criticised in a number of ways, including: a lack of knowledge (among GPs) about MS, a lack of support, poor attitude and for providing no information.

Before reading negative statements about diagnosis and the consultant neurologists it should be borne in mind that being diagnosed as having MS is in itself a negative experience and is likely to influence a person's view of the situation and the people involved. It should also be noted, at this point, that the questionnaire data showed that more often than not information had been provided at diagnosis and the situation had improved dramatically over the last seven years.

The following comments serve to illustrate these views.

***"....the neurologist said you have an incurable disease, it could progress, there is nothing we can do, goodbye..."***

***"....I was told I had MS and that it was incurable.....I was lying there thinking I was going to die, he did not explain anything to me...."***

***" I felt that when I got told I'd got MS it was cheerio and get on with it. They don't tell you anything.."***

***" my wife got told I had MS but was told not to tell me as I wouldn't cope, it was 8 years before she told me..."***

The need for information and the impact of information, at this time, is illustrated by the following quotes:

***"... I found out what was the worst that might happen, what was the best and decided I would be happy with what lay in-between..."***

***" When you get your diagnosis it is like you fall into a big pit, it is only information that brings you out..."***

Less negative descriptions of diagnosis were described when people thought they had a more life threatening condition or when they were told quickly after the onset of symptoms:

***"it was quite a relief it was MS because it could have been a lot worse"***

***"I was told reasonably quickly. I was taken into hospital, had all the tests and at the end of the week the specialist came along and informed me I had MS ..."***

The need for positive emotional support at the time of diagnosis is evident from the following comment:

***"... what you desperately need when you're diagnosed with MS is support of some sort or another.."***

#### ***Implications for information provision***

- ◆ information needs to be consistently provided at diagnosis
- ◆ information needs to be provided in a positive and supportive emotional environment.

#### **Attending therapy centres**

Attending the therapy centre was one of the most positive experiences described by respondents. It should be noted, however, that focus group sessions were held in therapy centres and most of the respondents attended the therapy centre and that this response is specific to this group. One reason for the popularity of therapy centres was the opportunity to meet other PWMS and the range of services provided in one place.

***".... I have aromatherapy, physiotherapy and the oxygen treatment and it is all done here (therapy centre) and I pay what I can afford for it.."***

#### ***Implications for information provision***

- ◆ newly diagnosed PWMS should be made aware of therapy centres.

#### **Talking to other PWMS**

As indicated above, another positive experience that was frequently discussed was talking to other people with MS. It was clear that other PWMS provided both emotional support and information. For example:

***".. it's saying - my little finger's been twitching like mad - and someone says - oh I've had that - and you think oh, I'm normal..."***

The importance of contact with other PWMS is borne out in the questionnaire data where other people with MS and GPs, despite critical comments about GPs, emerged as the two most common sources (10%) of useful information. These were closely followed by neurologists (9%); MS therapy centres (9%); the MS Society (head office) (9%), the MS Trust (7%), MS specialist nurse (7%) and the MS Society (local branch) (7%). Other sources including, for example, the library, the family and social services, accounted for the remaining sources of positive information.

#### ***Implications for information provision***

- ◆ the opportunity for PWMS to contact other PWMS should be facilitated
- ◆ information should be made available that points people to the cross section of agencies who can provide help.

### **Health care and health professionals**

One topic concerning health care was raised that, although not directly related to information needs does have certain implications. This was the lack of long term treatment through the NHS, and particularly the lack of physiotherapy. Many people mentioned the impossibility of having more than 6 weeks treatment on the NHS.

***"..you can have six weeks Physio and that is it. Then you try to find other places like this but you have to pay."***

***"They don't understand and they don't help. Six weeks is not enough ...I have to use a charity to get the treatment I need."***

The lack of free formalised health care possibly increases the need to become independently knowledgeable, quickly, following diagnosis.

One perception of PWMS was that the nature of the MS condition was at odds with health service provision:

***"The variability – you don't fit, the categories are rather rigid but the NHS and the special services don't have the flexibility to cope with a condition like MS where you can have good days and you can have bad days. "***

Despite negative comments, health care professionals were mentioned in a positive light more frequently than any other source. This group was followed, in order of preference, by voluntary organisations, family and friends and then the public. Positive situations were associated with '***gave advice***', '***gave information needed***', provided '***positive emotional support***', '***filled in forms***'. '***Positive emotional support***' and '***gave information needed***' were the two most common forms of positive support experienced. In addition, enabling a person to get involved in a research trial was also mentioned. Positive situations were also associated with accessibility and a positive relationship with the information provider.

***".. I rang up and asked for an appointment and she said he is here now if you want a word, and I was put through, it was like getting put through to god, now I can call whenever I have a problem.. "***

***"..my consultant and I treat my MS as a partnership..."***

***"....I went and saw [name deleted] and she wanted to support my wife, she said how much have you told her, and I said as much as I know, she said bring her in and I'll tell her a lot more. And she is a trained MS Nurse.."***

Consultants and GPs did, however, receive criticism as indicated in the previous section. Insensitivity characterised some cases as the following two quotations illustrate.

***"..He (The Consultant) said go away I will see you when you are in a wheelchair..."***

***" (GP) told me it was in my head and to go and see a psychiatrist..."***

Negative situations were associated with comments, such as, 'poor attitude', 'gives no information', 'lacks knowledge', 'not available'. It could be argued, of course, that it is unrealistic to expect GPs to be knowledgeable about MS given that the average GP only has two PWMS on their books. GPs could, however, have access to information on MS and be able to point people to appropriate information sources.

### ***Implications for information provision***

- ◆ Health care professionals need to understand the PWMS' information needs
- ◆ Health care professionals need to be trained to give the diagnosis and provide information in a sensitive manner.
- ◆ Health care professionals need to have access to information and 'signposting' material of relevance to PWMS.
- ◆ Health care professionals need to provide information proactively in a sensitive way and help PWMS to inform themselves.

### **General Public**

Respondents felt it necessary to note the significance of the positive attitudes held by the general public. This seemed to come as a surprise to PWMS and it took many people some time after diagnosis before they would ask for and accept help partly for reasons of pride but also because they were unaware of the willingness of people to help.

***"..I was sat outside an ice-cream shop and no-one was at the counter and they could not see me in my chair... these two boys asked if I wanted an ice-cream and went and got the man behind the counter...."***

***"I have to say how helpful people in general are.."***

***"It's amazing the number of people who compensate for you having it...they know you can't carry your pint, so maybe they help you, save you spilling it. People take you for what you are rather than what you used to be.."***

Conversely a lack of public knowledge about MS and disability can lead to negative situations, such as:

***"..they see the chair not the person..."***

***".... people walk in front of me when I am in my chair whilst I am looking in shop windows..."***

### **Implications for information provision**

- ◆ PWMS need to be aware that people generally are willing to help
- ◆ the public should be more aware of MS and the needs of disabled people in general.

### **The family and friends**

The family was cited as a source of support and understanding.

***"My family have been fantastic, very supportive. "***

***"..my family are brilliant and I've got three children and I am their mum and they think I'm wonderful, heaven knows why. They have been wonderful."***

***"..I'm lucky enough with my immediate family, they never look at my wheelchair and see it as a restriction, it's just something that has to be done.."***

Friends also offered a source of positive support, the nature of which has implications for how an information service should interact with a PWMS.

***"...I mean friends on the whole. They accept me. I say with MS it just takes me a bit longer than not with MS and they allow for that.."***

The relationship with the family was, however, not always positive. Negative experiences ranged from a lack of understanding of MS to a complete disregard for the person with MS.

***"...the lack of faith from other members of my family was quite hard, often I was accused of malingering..."***

***"... family and relatives... they don't always accept because we don't have a broken leg..."***

***".. I've got relatives who now - I've not heard from for months and months... they don't give a \*\*\*\* about me...."***

***"...no support from my husband and he had an affair with the friend I thought I could get support from.."***

These negative family situations may be exacerbated by the fact that the respondents said that it was not easy to communicate with the family about MS. In one focus group a copy of the audiotape was requested to play to the family 'so that they knew what it was like'.

### **Implications for information provision**

- ◆ appropriate information needs to be made available for the family of the PWMS
- ◆ PWMS need to be made aware that difficulty communicating with family about their MS is common
- ◆ Care professionals should not assume that the PWMS will get positive emotional or practical support from the family.

### **Filling in forms**

Help when filling in forms was seen positively. This was particularly the case with forms associated with state benefits.

***"..she sat and went through it with me, it was the way she said the questions, she showed me how to get what I needed.."***

***"....when I was filling in the form they (Citizens Advice Bureau (CAB)) said, you're going to get nothing for writing this rubbish. Don't lie but be pessimistic. You put down what they say and you get what you need, having help like that is wonderful...."***

### **Implications for information provision**

- ◆ guides as to how forms that a PWMS may encounter should be filled in, should be made available in conjunction with other MS information
- ◆ PWMS need to be informed about advocacy services
- ◆ PWMS need to be informed about how relevant services work and the mechanics of initiating support.

### **Disabled access**

Although not specific to PWMS, disabled access to buildings and access to facilities for the disabled was a subject often raised and is illustrated by the following quotes:

***".. there was no ramp into the pool, you had to either try and use the steps or just jump in.."***

***"..she said oh we have disabled toilets...they were up a spiral staircase.."***

***"...there are shops I can't get into because there are steps - you have to bang on the window to attract attention but very often I have to wait until they have cleared the shop of customers, so I don't get my turn.. it makes you feel very second class.."***

### **Implications for information provision:**

- ◆ Information about access to buildings and the facilities for the disabled needs to be made available.

### **Voluntary organisations and advice centres**

Voluntary organisations tended to be popular because they went some way towards offering a 'one stop shop' for information and positive support.

***"...I rang them [charity] up and said I didn't know about this and they went off and found out for me..."***

People also had unhelpful experiences with voluntary organisations.

***"we went to a meeting, we were patted on the head, told to sit over there and we will bring you a coffee, didn't go again..."***

***"They [charity] sent a man with 2 sticks to see me, I was terrified I was going to end up like that ..."***

Citizen's advice bureaux (CAB) received both positive and negative criticism:

***".. I went to Citizen's Advice, and she asked the questions, and it's the way she asked them, so when I filled it in I didn't get it but when she helped I did."***

***"... I went to the CAB and told them I'd got MS and they wanted me to fill in this form, fill out this one, wait for this, it was like, oh, it was too much.."***

### **Implications for information provision**

- ◆ An information service should be sensitive to the emotional and practical needs of PWMS.

### **Getting equipment**

Locating appropriate equipment for the person with MS was not always easy but can make a very significant difference to quality of life:

***"... it took me a long time but now they are delivering the bed this week, free of charge.."***

### **Implications for information provision:**

- ◆ PWMS need to be told where equipment can be seen, bought and possible ways to finance the purchase.

### **Finding out about entitlements**

Finding out about sources of financial support was a priority, particularly finding out about benefits and money to finance equipment.

***"I rang the Benefits Agency up and they said, yes, you can get this and this and this..."***

***" If I need a deposit for my mobility car I use the MS Society..."***

The first problem with benefits was finding out about entitlements; secondly finding out how to claim for it; and finally what forms to fill in and how to complete the right form correctly.

***"... if we had someone specific, that was not patronising, someone who knew about MS in the benefits agency.."***

The lack of information and help available from the Benefits Agency meant that people had been unaware what they could claim for and applications were refused due to incorrect completion of forms. One respondent expressed the view:

***"...the DSS or what's now called the Benefits Agency they are so protective of their money, it's as if it's their own personal money, they do not give you any help at all..."***

#### ***Implications for information provision***

- Information should be made more widely available on how to claim for sources of financial support in a form that is easy to understand.

#### ***Finding out about MS symptoms and drugs***

The need to find out about symptoms was, generally, evident. The quantitative data (see table 9) did show, however, that not everyone wanted to be informed on the same specific areas, at diagnosis, that could be assumed to be relevant. This could be because people only wanted to know about a specific symptom that related to their current condition or they did not want to be overwhelmed with negative scenarios of what might happen.

The need to know about drug treatments as well as current research trials was also evident. The reasons for the latter were that trials perhaps represent hope for the future and that people wanted to be kept up to date with new developments. People stated that they would also like to have the opportunity to take part in trials.

#### ***Implications for information provision***

- Information should be made available on the range of symptoms that could be experienced by PWMS. However PWMS need to be given the choice as to when they receive this information
- PWMS should be kept up to date on drug treatments and on current research trials.

#### ***Stopping work and the lack of social life and a decline in ability to do things***

Significant life changes are likely to be associated with having MS including , in some cases, giving up work, although it should be noted that the lives of people with minor symptoms or very sporadic symptoms may be relatively

unchanged. In the focus groups the impact of giving up work because of MS was felt to be significant. In particular the associated sense of isolation as well as the obvious gap in their lives was raised. The following comments illustrate these views:

***"...The biggest things, the repercussions of having to give up work, not just financial, because there's a lot more to work than just finance, some people would disagree but, well, psychological, you do a job, well most people do a job and enjoy the job and to suddenly, just like that, to most people it's a big block gone..."***

***"I seemed to know a vast amount of people and it all just stopped. I was a bar maid – very sociable and I worked in a post office in the mornings I knew a lot of people. I would give out the money in the morning and take it off them at night. From being amongst them and then being ill and alone at that stage, I couldn't carry on, I couldn't cope."***

Voluntary associations including MS local branches helped to ameliorate this situation. Not everyone, however, found it easy to join such groups:

***"...why don't you go to the MS Society you think well these people are going to be ill, and you're very blinkered and in fear.. you think I am not ill and I'm going to go in there and see all those ill people, I will think that I am going to be like them..."***

Lastly, people noted the negative experience of being able to do less, due perhaps to fatigue or mobility problems.

***"I used to play golf all the time.. they told me I could only come as a guest.. I was too slow and holding up play. That made me feel terrible."***

#### ***Implications for information provision***

- PWMS should be informed about local MS groups
- Information should be provided on employment issues, the possible implications of giving up work and possible coping strategies
- PWMS need to be informed about alternative social networks that they could use
- PWMS need positive information on, for example, things that other people can do and have done, such as leisure pursuits or further study, in contrast to the overwhelming information on the negative aspects of having MS.

### **Key themes identified in the audio diary data**

As stated earlier the intention of audio diaring was primarily to find out if data gathered in this way would give a different insight from that generated by focus groups and questionnaires. Only five people were asked to take part. The people who did take part all experienced either cognitive or physical symptoms of MS or both.

In general the data provided an insight into the day-to-day experience of a PWMS who had a number of symptoms including mobility problems. Greater detail was provided on the impact of MS than was found in either the focus group data or the questionnaire data.

Among the respondents the physical impact of MS and the need for aids was particularly evident and also how important these aids were for social participation. For example, people experienced difficulty with: getting out of bed, bathing, dressing, dressing children, cooking, shopping, walking a distance and driving. Aids such as an electric bed, a transfer board, an adapted car, as well as services such as meals on wheels made a considerable difference to the PWMS. PWMS therefore need to be aware of aids and services and how to access them when needed.

The range of possible symptoms of MS also became evident. These included fatigue, difficulty with concentration, stiff legs, numb hands, insomnia, headaches, back spasm, loss of balance, stress, diplopia and incontinence. Witnessing this range of symptoms helped to indicate why, in the focus groups, as well as in the quantitative data, the understanding of symptoms is an important topic for PWMS.

Symptoms were discussed in relation to how people dealt with them, for example, making it a conscious strategy to take rest. It was also evident that maintaining a positive attitude when coping with these symptoms was important and that the symptoms might negatively affect self-esteem. Where possible, therefore, information should be provided in a positive fashion i.e. how people have managed their symptoms in addition to information about particular symptoms.

The self-esteem the PWMS and the knowledge and understanding of symptoms by other people (non-PWMS) was connected. A lack of understanding of MS by work colleagues, friends and family, exacerbated by the fact that symptoms of MS might not be visible, sometimes led to a negative view of the PWMS who felt they were branded as a shirker. It was also difficult for the PWMS to explain their condition and how, for example, they sometimes needed to take things slowly. As indicated from the focus group data, information therefore should be more widely disseminated to the public about MS particularly those who regularly come into contact with the PWMS.

Overall the audio diaries made it very clear that the PWMS should be seen first and foremost as a person who wants to take part in life rather than a

PWMS. This could include, for example, undertaking work, taking part in leisure pursuits, looking after the family etc. Being able to do so was extremely important for the self-esteem and quality of life of the PWMS. Information providers should therefore take this into account when dealing with PWMS and should not concentrate solely on information specific to MS.

### **Quantitative data analysis and findings**

As stated 4100 questionnaires were distributed to PWMS and 2030 were returned. This gave a return rate of approximately 49%.

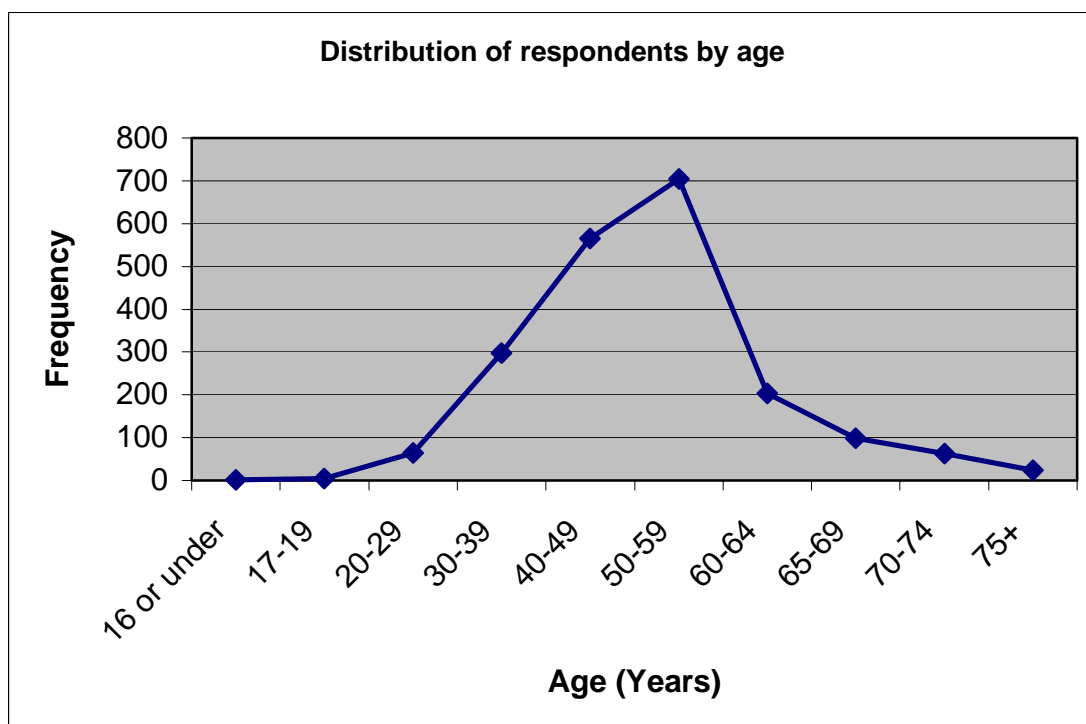
### **Background on respondents**

#### **Gender**

There were 1509 female respondents and 512 male respondents with 9 people who did not disclose their gender. This gave a female to male ratio of approximately 3:1. This compares with the national norm of 2 females to 1 male.

#### **Age**

A graph showing the distribution of the ten different age groups is shown in Figure 1.

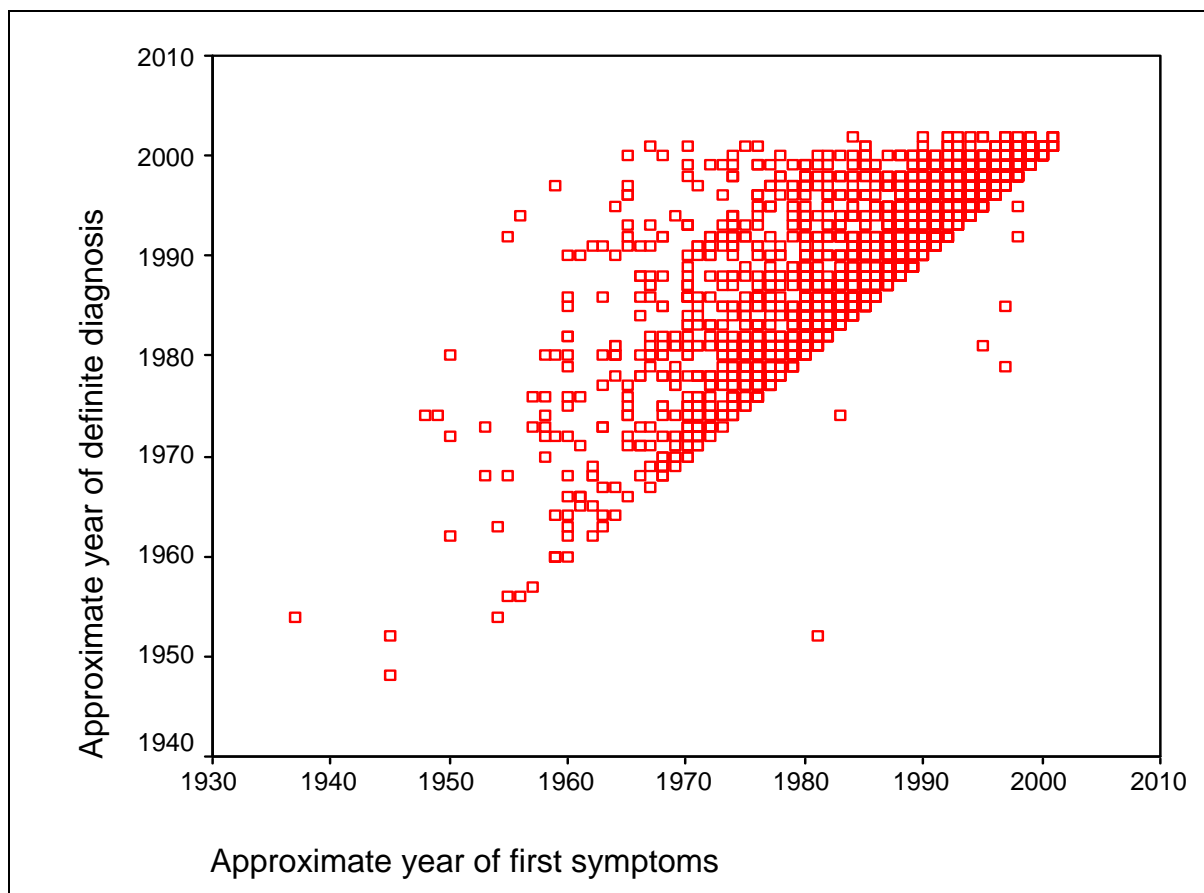


**Figure 1** *Distribution of respondents by age*

### Year of first symptoms and year of diagnosis

The range of dates for people experiencing their first symptoms ran from 1937 up to 2001. 50% of respondents had experienced their first symptoms after 1986. 20% had experienced their first symptoms after 1994.

The year of first symptoms was compared with the year of diagnosis (Figure 2). In figure 2 the y axis represents the year of diagnosis. The x axis represents the year of first symptoms. Each square represents respondents. For each square one can therefore identify the year of first symptoms on the x axis and the year of diagnosis on the y axis. It can be seen that in some cases there was significant gap between first symptoms and diagnosis. The seven outliers where the year of diagnosis precedes the year of first symptoms are due to incorrect data given by the respondents.



**Figure 2** Year of first symptoms and year of diagnosis

The year of diagnosis for respondents is detailed in Table 4. The questionnaire was completed by a range of people with MS, with 21.6% having been diagnosed within the last 5 years and 53% had been diagnosed in the last 10 years. Nearly 10% of respondents had been diagnosed over 25 years ago.

	<b>Year of diagnosis</b>	<b>Frequency</b>	<b>Percentage</b>
	Pre 1977	161	9.3
	1978	31	1.5
	1979	25	1.2
	1980	43	2.1
	1981	57	2.8
	1982	45	2.2
	1983	38	1.9
	1984	45	2.2
	1985	66	3.3
	1986	65	3.2
	1987	50	2.5
	1988	68	3.3
	1989	56	2.8
	1990	70	3.4
	1991	75	3.7
	1992	107	5.3
	1993	63	3.1
	1994	110	5.4
	1995	101	5.0
	1996	102	5.0
	1997	114	5.6
	1998	155	7.6
	1999	127	6.3
	2000	95	4.7
	2001	44	2.2
	2002	17	0.8
	Total	1951	96.1
Missing	System	79	3.9
Total		2030	100.0

**Table 4** *Year of diagnosis*

Of the 2030 people surveyed 79 did not respond to the question.

### Current employment status

The employment status of the respondents is shown in Table 5.

	<b>Employment Status</b>	<b>Frequency</b>	<b>Percentage</b>
	Full-time	225	11.1
	Part-time	221	10.9
	Retired	519	25.6
	Voluntary	55	2.7
	Seeking work	25	1.2
	Unable to work	715	35.2
	In education	8	0.4
	Other	123	6.1
	Total	1891	93.2
Missing	System	139	6.8
Total		2030	100.0

**Table 5** *Employment status of respondents*

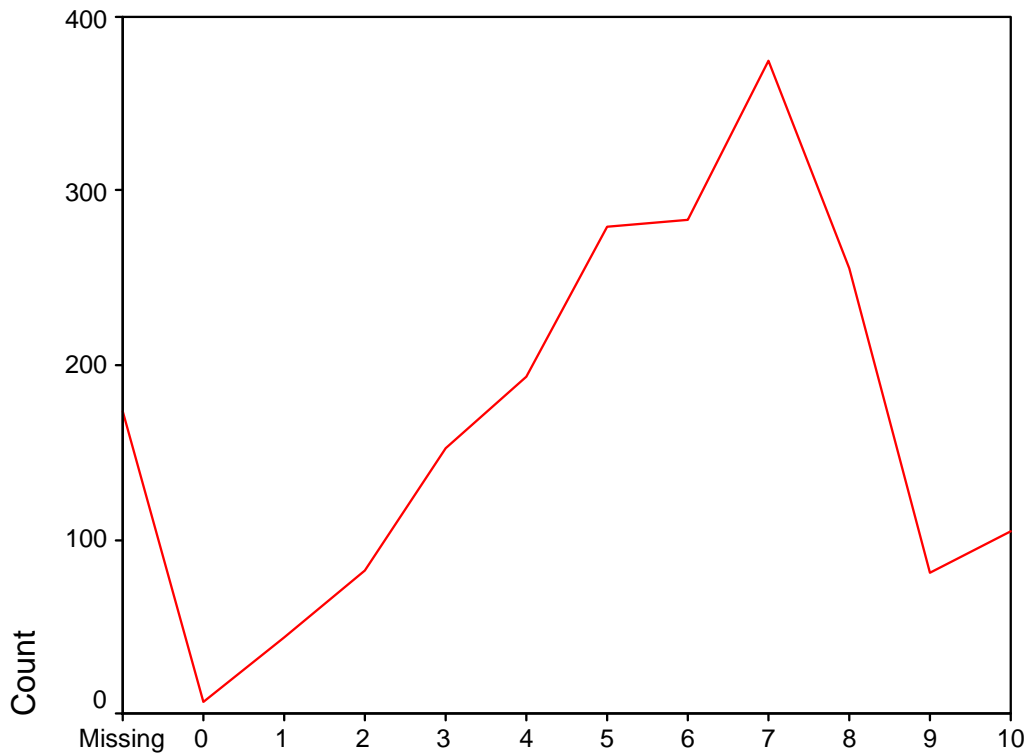
Approximately thirty five percent of respondents were unable to work. Unable to work was interpreted as 'could not work because of MS', whereas retired meant having voluntarily or through age retired from work. Twenty one percent were in general employment (11% of people full-time employment and 10% in part-time employment).

When asked if MS had affected their employment status at any time, 1441 respondents (71%), replied that it had, whilst 521 (26%) answered that it had not.

### Rating of symptoms and disabilities

People were asked to rate their symptoms and disabilities on a scale of 0-10 where 0 indicated no symptoms and 10 represented severe symptoms.

174 people declined to answer this question; the remaining responses are detailed in Table 6 and graphically in Figure 3.



Please rate your symptoms and disabilities overall.

**Figure 3** Respondents' assessment of their MS severity

The majority of respondents rated themselves at level 7 and 25% of respondents saw themselves at level 4 or under.

The severity with which MS affected the person was statistically associated with how difficult each PWMS found it to get information, and also with the preferred format for information and the relative importance of information.

This was generally to be expected as the more severe a person's symptoms the more likely he/she is to have required a wider range of information together with more specific and specialist information which might be more difficult to find. Those with severe symptoms may also experience physical and psychological obstacles to finding information, such as fatigue, mobility problems or difficulty with concentration.

	Symptoms	Frequency	Percentage
	0	6	0.3
	1	44	2.2
	2	82	4.0
	3	152	7.5
	4	193	9.5
	5	280	13.8
	6	283	13.9
	7	375	18.5
	8	255	12.6
	9	81	4.0
	10	105	5.2
	Total	1856	91.4
Missing	System	174	8.6
Total		2030	100.0

**Table 6** Respondents' ratings of symptoms and disabilities

The majority of people responding to the questionnaire classed their symptoms and disabilities higher than 5 on a scale of 0-10. Sixty percent of people believed they were considerably affected. Only 105 (5%) PWMS reported severe symptoms.

### Diagnosis

1459 respondents (72%) received their diagnosis from a consultant neurologist, whilst 250 (12%) were informed by a GP. Nearly 17 (1%) of people were informed by a relative. Table 7 details the frequencies of diagnosis by different personnel.

Who did you receive your diagnosis from?	Frequency	Percentage
Consultant Neurologist	1459	71.9
Other hospital Doctor	211	10.4
Relative	17	0.8
Nurse	6	0.3
GP	250	12.3
Not had a diagnosis	8	0.4
Other	47	2.3

**Table 7** Source of diagnosis

### **Information provision at diagnosis**

Approximately 861 (42%) of respondents said that they received no information at the time of their diagnosis (see Table 8).

People were given information on possible symptoms and drug treatments, as well as an indication of the likely course of the condition. Few people received information on alternative therapies, counselling or were given work related information.

Only 212 (10%) received information about MS specialist nurses and 91 (4%) received information about occupational therapy.

Little information was provided on possible psychological symptoms and only 113 (5.6%) were given any information for their family.

Table 8 shows the topics of information that were generally provided at diagnosis, as well as when information was not given. Respondents selected more than one topic. Between 10 and 11 people did not respond to this question.

### ***Implications for information provision***

- ◆ Information should be made available, consistently, at diagnosis
- ◆ Information provided should cover the range of information needs.

When comparing the frequencies of those who received information on a certain topic and those who did not it seems likely that many people with MS were not given information they needed.

To determine whether the data was representative of the newly diagnosed the same data was analysed but was limited to the respondents who had been diagnosed within the last five years (Table 9). Three respondents in this category did not reply to this question.

<b>What information were you given at the time of your diagnosis?</b>	<b>Given</b>	<b>% Given</b>	<b>Not Given</b>	<b>% Not Given</b>
<b>Was any information given at diagnosis?</b>	1159	57.1	861	42.4
<b>Possible physical symptoms</b>	494	24.3	1526	75.2
<b>Possible drug treatments</b>	345	17.0	1675	82.5
<b>Indication of disease course</b>	308	15.2	1711	84.3
<b>Physiotherapy</b>	264	13.0	1756	86.5
<b>Organisation addresses</b>	264	13.0	1756	86.5
<b>MS specialist nurse</b>	212	10.4	1808	89.1
<b>Other</b>	212	10.4	1808	89.1
<b>Information on diet</b>	204	10.0	1816	89.5
<b>Managing symptoms</b>	158	7.8	1862	91.7
<b>Information on exercise</b>	144	7.1	1875	92.4
<b>Driving</b>	115	5.7	1905	93.8
<b>Information for family</b>	113	5.6	1906	93.9
<b>Contact for group of newly diagnosed</b>	93	4.6	1927	94.9
<b>Occupational therapy</b>	91	4.5	1928	95.0
<b>Benefits and Entitlements</b>	82	4.0	1938	95.5
<b>Possible psychological symptoms</b>	64	3.2	1956	96.4
<b>Counselling</b>	50	2.5	1970	97.0
<b>Work related information</b>	44	2.2	1976	97.3
<b>Alternative therapies</b>	25	1.2	1995	98.3

Table 8 *Information provision at diagnosis*

<b>What information were you given at the time of your diagnosis?</b>	<b>Given</b>	<b>% Given</b>	<b>Not Given</b>	<b>% Not Given</b>
<b>Was any information given at diagnosis?</b>	396	71.6	154	27.8
<b>Possible physical symptoms</b>	163	29.5	387	70.0
<b>Possible drug treatments</b>	163	29.5	387	70.0
<b>MS specialist nurse</b>	163	29.5	387	70.0
<b>Physiotherapy</b>	108	19.5	442	79.9
<b>Indication of disease course</b>	106	19.2	444	80.3
<b>Organisation addresses</b>	95	17.2	455	82.3
<b>Other</b>	71	12.8	499	90.2
<b>Information on diet</b>	64	11.6	486	87.9
<b>Managing symptoms</b>	62	11.2	488	88.2
<b>Information on exercise</b>	60	10.8	489	88.4
<b>Information for family</b>	51	9.2	499	90.2
<b>Driving</b>	46	8.3	504	91.1
<b>Contact for group of newly diagnosed</b>	42	7.6	508	91.9
<b>Occupational Therapy</b>	38	6.9	512	92.6
<b>Benefits and Entitlements</b>	30	5.4	520	94.0
<b>Possible psychological symptoms</b>	26	4.7	524	94.8
<b>Counselling</b>	26	4.7	523	94.6
<b>Work related information</b>	16	2.9	534	96.6
<b>Alternative therapies</b>	11	2.0	539	97.5

**Table 9** *Information given at diagnosis 1997-2002 (553 respondents)*

It appears that the situation has changed and there has been a 14% increase in information being given within the last five years. A significant number of PWMS, however, still indicated that they had not received information (28%). Information provision on drugs has increased by 13% and information about

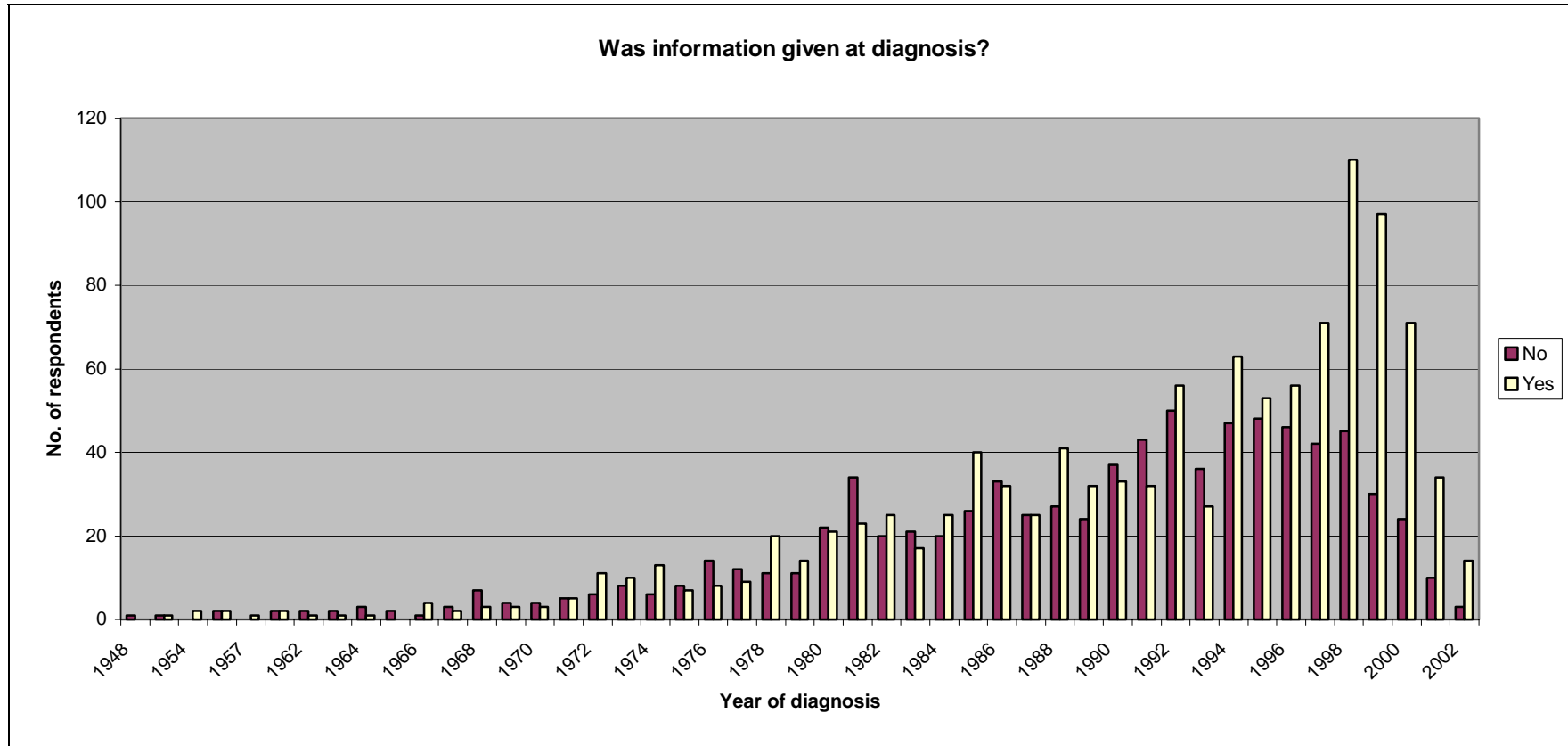
MS nurses by 19%. Information for the family and also about counselling has increased significantly indicating a more holistic approach to information provision over the last five years (although it was only provided in a small number of cases).

***Implications for information provision***

- ◆ information provision at diagnosis needs to continue to improve

Figure 4 shows information provision compared with the year of diagnosis. This clearly indicates that information provision has improved dramatically over the last seven years. It should be noted that Beta Interferon was licensed in the UK in 1995. In 1996 the number of MS specialist nurses increased from 3 to 35 and the numbers have subsequently risen further.





**Figure 4** *Information provision at diagnosis by year*

### What information would PWMS like to be given at diagnosis?

Analysis of the data has already indicated that there had been uneven provision of information at diagnosis. When asked what information PWMS would have liked to be given at the time of their diagnosis there was a positive response for most topic areas.

What information would you have liked?	Liked	% Liked	Not liked	% Not liked
Managing symptoms	1334	65.7	685	33.7
Possible drug treatments	1232	60.7	787	38.8
Indication of disease course	1121	55.2	897	44.2
Possible physical symptoms	1118	55.1	901	44.4
Information on exercise	1093	53.8	926	45.6
MS specialist nurse	1089	53.6	929	45.8
Information for family	1072	52.8	947	46.7
Information on diet	1017	50.1	1002	49.4
Benefits and Entitlements	995	49.0	1024	50.4
Physiotherapy	986	48.6	1031	50.8
Contact for group of newly diagnosed	948	46.7	1071	52.8
Alternative therapies	939	46.3	1080	53.2
Organisation addresses	913	45.0	1106	54.5
Possible psychological symptoms	885	43.6	1133	55.8
Counselling	804	39.6	1215	59.9
Work related information	714	35.2	1305	64.3
Driving	637	31.4	1380	68.0
Occupational Therapy	570	28.1	1449	71.4
Other	115	5.7	1906	93.9

**Table 10** Information that respondents would have liked to have been given at diagnosis (all respondents)

Table 10 shows the areas in which people wanted to be given information when diagnosed. These included managing symptoms and possible drug treatments, which were areas where many people said they had been given information. The number of people who wanted information on these topics, however, far exceeds those that said they received it.

It is important to note that a significant proportion of respondents did not want information. This may be because the topic was not felt to be relevant or they did not want information on that topic for other reasons.

Many of the topics seem to have divided the respondents as to whether they would have wanted information or not. This could be due to people's attitude to information, that is whether they are 'monitors' (Baker 1994) and also due

to the impact and the severity of the condition and people's personal circumstances.

This highlights the need for individually tailored information provision to ensure that people with MS are getting the information that they need and are not being left uninformed or conversely inundated with irrelevant or unwelcome details.

Again, data for people diagnosed within the last five years were analysed to see if the demand for information at diagnosis had changed. Little change can be seen to have taken place, indicating that there is a consistent demand for these categories of information. Table 11 shows the responses.

What information would you have liked?	Liked	% Liked	Not liked	% Not liked
Managing symptoms	362	65.5	188	34.0
Possible drug treatments	318	57.5	232	42.0
Possible physical symptoms	295	53.3	255	46.1
Indication of disease course	294	53.2	256	46.3
MS specialist nurse	292	52.8	258	46.7
Information for family	278	50.3	272	49.2
Contact for group of newly diagnosed	271	49.0	279	50.5
Information on exercise	264	47.7	286	51.7
Possible psychological symptoms	256	46.3	294	53.2
Information on diet	254	45.9	296	53.5
Benefits and entitlements	245	44.3	305	55.2
Alternative therapies	245	44.3	305	55.2
Physiotherapy	231	41.8	318	57.5
Organisation addresses	226	40.9	324	58.6
Counselling	226	40.9	324	58.6
Work related information	187	33.8	363	65.6
Driving	169	30.6	380	68.7
Occupational therapy	137	24.8	413	74.7
Other	40	7.2	511	92.4

**Table 11** Information liked at diagnosis 1997-2002 (553 respondents)

**Implications for information provision**

- ◆ information should be available, on all the areas listed above, at diagnosis
- ◆ information should be provided in a way that is sensitive to the PWMS' psychological, emotional and physical condition
- ◆ PWMS should be able to choose the information they want to receive.

## Who do you go to for useful information on MS?

The following table (Table 12) lists the people, places or organisations that the respondents were using for provision of useful information on MS.

Information provider	Percentage
Other people with MS	10
GPs	10
Neurologist	9
MS Therapy Centre	9
MS Society (head office)	9
MS Trust	7
MS specialist nurse	7
MS Society (local branch)	7
Physiotherapist	6
Other (generally the Internet)	5
Library	5
Friends	4
Alternative therapist	2
Family	2
Other local support group	2
Benefits Agency	1
Social Services	1
Dietician	1
Carer	1
Citizens Advice Bureau	1
Pharmacist	1

**Table 12** Sources of useful information (all respondents)

From this it is clear that the two most common sources of useful information were other people with MS (10%) and GPs (10%), followed by neurologist (9%). Voluntary organisations and MS nurses can also be seen to be a significant source of information.

Government agencies such as Social Services and the Benefits Agency were seldom used; neither were the Citizens Advice Bureaus or pharmacists.

When people mentioned going to "Other" places for information they usually referred to the Internet.

### **Implications for information provision**

- ◆ PWMS need to be made aware of the full range of people and organisations who could provide useful information
- ◆ Information on the range of services should be made more widely available.

## Difficulty finding information

People were asked to rate how difficult it was to find information on various topics concerning MS. They were given a 5 point scale:

- Very difficult
- Difficult
- Slightly difficult
- Not at all difficult
- Not needed

'Not needed' indicated that the person completing the questionnaire had not yet tried to find information on the topic. The results are shown in Table 13, below.

Topic	Very difficult (%)	Difficult (%)	Slightly difficult (%)	Not at all difficult (%)	Not needed (%)
Access and transport	9.0	19.2	21.2	13.3	32.7
Access to MS research trials	24.2	21.6	19.8	17.7	11.3
Aids and appliances	4.8	15.9	24.5	29.4	21.0
Complementary therapies	10.6	15.6	21.2	32.2	13.5
Balance, problems walking	16.5	24.7	26.2	20.4	21.4
Benefits and entitlements	14.7	23.6	25.1	21.6	10.5
Bowel and bladder disturbances	11.2	20.5	27.4	22.1	15.2
Drug treatments	20.0	24.2	21.0	21.3	8.3
Emotional changes	18.8	24.7	20.8	11.2	18.0
General information on MS	5.1	11.7	25.6	52.2	2.0
General symptom management	9.9	21.8	32.9	24.4	5.1
Home modifications	10.9	16.9	20.0	18.3	29.7
Information for family/friends	8.5	15.4	22.9	29.6	17.6
Leisure activities and holidays	15.0	16.5	18.7	13.7	31.4
Memory problems	14.1	23.3	21.6	11.8	24.7
New and unusual symptoms	15.0	26.7	27.4	13.1	11.8
Nutritional advice	9.6	16.8	23.7	32.7	12.6
Occupational therapy	8.9	15.0	19.7	24.7	25.8
Organisation address	3.3	6.9	21.3	55.2	7.6
Physiotherapy	10.0	14.1	21.5	40.4	10.3
Research	11.2	17.2	26.2	33.4	6.0
Stress	13.8	22.9	25.4	16.3	15.7
Visual problems	9.5	17.1	24.6	23.0	21.0
Working and MS	14.2	16.5	16.1	12.3	34.6

**Table 13** Percentages for difficulty finding information on particular topics (all respondents)

The topic that was predominantly seen as very difficult to find information on was, **Access to MS research trials**.

Being given information about access to MS research trials allows people the option of being involved in the development of treatments or of a cure as well as being aware of their progress.

Those topics which were most frequently seen as difficult to find information on were: **Drug treatments, emotional changes and working and MS**.

Disease modifying drug therapies have been notoriously difficult to access and therefore information about them has been equally difficult to find. Knowing about emotional changes will help people understand why they are feeling the way they do. Finding out about working and MS will perhaps help minimise the impact MS has on their day to day life.

Areas that were seen as slightly difficult to find information on were: **Access and transport, Balance and problems walking, Benefits and entitlements, Bowel and bladder disturbances, General symptom management, Home modifications, Leisure activities and holidays, New and unusual symptoms, Stress and Visual problems**.

People responded that the following topics were not at all difficult to get information on: **Aids and appliances, Complementary therapies, General information on MS, Information for family and friends, Nutritional advice, Occupational therapy, Organisation addresses, Physiotherapy and Research**.

The dataset on people who had been diagnosed in the last five years was analysed separately. It was found that the responses were similar. The only case where a significant change had occurred was information on bladder and bowel disturbances where the level of difficulty in getting access to information had dropped by 6%.

Referring back to the data on the provision of information at diagnosis; information that was frequently not given was on drug treatments, working and MS and possible psychological symptoms. This echoes the level of difficulty that people experienced when trying to get information on these topics.

#### **Implications for information provision**

- ◆ Information on current research and research trials should be made more widely available as well as on drug treatments, emotional changes and working and MS (in addition to the other topics).

#### **Importance of Information**

People were asked to rate the importance of the different topics. They were given a 4 point scale;

- Very important
- Important
- Not very important
- Unimportant

Table 14 shows the percentages for each level of importance for the various topics.

Those areas that over 40% of respondents felt were **very important** to have information on were: ***Balance and problems walking; Benefits and entitlements; Bowel and bladder disturbances; Drug treatments and Research.***

Areas that were **important** to over 40% of respondents included: ***Access to MS research trials; Aids and appliances; Complementary therapies; Emotional changes; General information on MS; General symptom management; Information for family and friends; New and unusual symptoms; Nutritional advice; Organisation addresses; Physiotherapy; Research; Stress; Visual Problems.***

Topic	Unimportant (%)	Not very important (%)	Important (%)	Very important (%)
Access and transport	18.4	25.4	30.8	21.9
Access to MS research trials	3.4	14.7	42.3	36.8
Aids and appliances	9.9	19.8	41.1	25.3
Balance, problems walking	4.0	7.3	37.6	47.6
Benefits and entitlements	5.8	8.7	38.5	44.1
Bowel and bladder disturbances	5.6	10.5	37.7	43.3
Complementary therapies	6.0	22.5	43.2	24.8
Drug treatments	1.9	8.3	36.5	50.6
Emotional changes	5.0	17.0	41.9	32.3
General information on MS	1.1	6.8	50.2	39.5
General symptom management	0.8	5.8	47.1	43.3
Home modifications	11.8	23.1	36.0	25.5
Information for family/friends	7.1	23.5	46.4	18.9
Leisure activities and holidays	16.4	33.7	31.9	14.2
Memory problems	8.3	20.4	39.9	27.5
New and unusual symptoms	2.3	8.6	45.6	40.3
Nutritional advice	5.8	19.7	46.6	24.5
Occupational therapy	11.4	24.2	39.5	20.4
Organisation address	3.9	22.2	51.5	18.0
Physiotherapy	4.2	11.9	40.8	39.5
Research	1.3	9.8	42.8	43.1
Stress	6.0	17.0	42.4	30.7
Visual problems	7.1	15.6	42.3	31.2
Working and MS	25.5	20.1	26.7	20.9

**Table 14** Percentages for importance of information (all respondents)

Clearly most people felt that most topics were important or very important.

In fact there was only one topic that was classed as not very important and that was ***Leisure activities and holidays***.

In general it can be seen that few respondents indicated that categories of information were unimportant. Those categories that were indicated as unimportant by over 10% of respondents included ***Working and MS (26%)***; ***Occupational therapy (11%)***; ***Leisure activities and holidays (16.4%)***; ***Access and transport (18%)***.

People who had been diagnosed in the last five years generally stated the same topics were important as those identified by the total respondent population. ***Access and transport*** decreased in importance by 6% as did ***general symptom management***. In comparison ***working and MS*** increased in importance by 11%, ***new and unusual symptoms*** by 8% and ***stress*** by 6%. These changes may indicate the situation of the newly diagnosed i.e. they generally have less severe symptoms hence less demand for ***access and transport*** but are very concerned about their symptoms.

#### ***Implications for information provision***

- ◆ Information should be made available to PWMS on all topics
- ◆ Particular effort needs to be made to provide information on topics that PWMS thought very important.

#### **How do you prefer to receive information?**

For the list of topics mentioned in the previous two sections respondents were asked to choose what format or way of presenting the information they would like.

The questionnaire helped to identify the most appropriate medium for providing information on different topics.

#### **Face to face**

Balance, problems walking  
 Bowel and bladder disturbances  
 Drug treatments  
 Emotional changes  
 General symptom management  
 Memory problems  
 New and unusual symptoms  
 Occupational therapy  
 Physiotherapy  
 Stress  
 Visual problems

#### **Leaflets**

Access and transport  
 Aids and appliances  
 Complementary therapies

Benefits and entitlements  
Home modifications  
Information for family and friends  
Leisure activities and holidays  
Nutritional advice  
Organisation addresses  
Working and MS

**Newsletter**

MS research trials  
Research

**Magazine**

General information about MS

Generally the most preferred formats were (in order of most frequently preferred):

- Face-to-face
- Leaflet
- Newsletter
- Magazine

The least preferred formats were (in order of least popular):

- Audio cassette
- Over the telephone
- CD-ROM

The impact of visual, memory and dexterity problems on PWMS has a bearing on which format is most useful for information provision. This tends to suggest that information should be available in a range of formats and that people with MS should have access to different formats for different information topics and at varying times and stages of their condition.

Where people were asked whether their MS affected how they found information there appeared to be an association between whether or not MS affected how the person found information and the difficulty in finding information. Fatigue was the most common factor, selected by 47% of respondents, saying it did affect finding information. This was followed by mobility for 45% of respondents. Overall 60% of respondents said their MS affected finding information.

Clearly sight, mobility, dexterity, fatigue, memory and concentration need to be taken into consideration when producing information for people with MS, to ensure that a suitable format is used, or even a range of formats are made available to encompass the range of symptoms which impact on their information behaviour.

Table 15 shows the percentages of people who express a need for particular formats across all of the topics. Again the same data was analysed for people diagnosed in the last five years. Changes in response rate, however, did not exceed 3%.

***Implications for information provision***

- ◆ Information should be provided in a variety of formats to cater for the needs of individuals
- ◆ Information providers should note the impact of, in particular, fatigue and mobility as well as other cognitive and physical factors on information use and hence provision.

Topic	Leaflet	Book	Video	CD-Rom	Magazine	News-letter	Audio Cassette	E-mail	Face to Face	Over telephone	Internet
Access and transport	41.5	2.6	2.8	1.2	9.1	16.9	0.8	2.6	13.2	4.6	4.6
Access to MS research trials	18.0	1.8	2.6	0.9	10.7	27.5	0.8	4.5	17.1	3.1	6.7
Aids and appliances	29.9	3.0	5.0	1.2	16.5	13.3	0.6	1.9	22.9	1.6	4.0
Complementary therapies	24.6	6.8	3.7	1.0	17.2	19.0	0.8	2.5	17.9	1.7	4.7
Balance, problems walking	18.7	5.0	6.3	1.1	9.2	10.7	1.0	1.8	41.8	0.9	3.4
Benefits and entitlements	36.4	4.5	1.6	0.9	6.4	13.1	0.7	2.0	25.9	4.5	3.9
Bowel and bladder disturbances	26.1	5.5	2.3	0.9	8.3	10.1	0.9	1.7	39.9	1.0	3.3
Drug treatments	17.0	3.4	1.9	0.9	9.6	18.2	0.8	2.6	39.0	1.4	5.1
Emotional changes	20.2	6.3	2.5	0.7	10.4	10.3	0.9	1.6	42.8	1.2	2.9
General information on MS	18.8	11.3	3.7	1.4	21.2	19.2	1.1	2.0	14.4	0.7	6.3
General symptom management	18.4	11.8	4.6	1.2	13.1	11.7	0.8	1.4	32.0	1.0	4.0
Home modifications	29.6	3.6	6.4	0.9	10.4	9.2	0.6	1.3	32.3	2.1	3.5
Information for family/friends	38.7	9.0	4.9	0.5	15.7	12.8	0.5	1.5	12.1	0.4	3.8
Leisure activities and holidays	28.4	3.3	5.8	1.0	23.5	13.4	0.5	1.7	6.5	0.4	6.7
Memory problems	26.0	8.2	3.5	0.9	10.6	10.2	1.0	1.7	34.1	0.5	3.5
New and unusual symptoms	16.9	5.5	3.2	0.9	9.8	12.7	0.7	1.8	42.8	1.6	4.1
Nutritional advice	27.7	8.9	2.8	1.1	15.1	12.6	0.4	1.7	24.6	0.9	4.3
Occupational therapy	24.5	2.0	4.7	0.9	8.9	11.3	0.4	1.6	40.9	1.2	3.6
Organisation address	40.9	4.0	1.2	1.0	14.2	19.4	0.9	2.8	5.7	1.5	8.3
Physiotherapy	19.6	2.7	5.1	0.7	7.5	11.3	0.5	1.7	46.7	1.7	2.5
Research	20.2	3.2	2.9	1.4	18.7	26.1	0.9	3.5	13.1	1.3	8.7
Stress	22.3	5.4	3.0	0.9	11.4	10.4	0.9	1.7	38.9	1.6	3.4
Visual problems	20.3	4.0	4.6	0.6	9.1	9.4	4.7	1.4	41.9	1.1	2.8
Working and MS	31.0	4.0	4.5	0.9	14.0	13.3	0.7	1.8	23.6	1.8	4.5

**Table 15** Preferences relating to format of information provision (all respondents)

## Part 4: Conclusions and recommendations

The findings corroborate previous smaller scale studies into the information needs of people with MS, in particular, Robinson et al. (1996) and Baker (1997), identifying similar categories of information need. In addition other information needs have been made apparent and the importance of different categories of information and the barriers that are currently inhibiting PWMS' access to information have been identified. The following draws on the findings of the study and recommends solutions.

### ***PWMS and information***

The qualitative data made it very clear that the PWMS should be seen as a person who is likely to want to play an active role in life. This could include, for example, being an employee, parent, partner, going on holiday etc. Being able to do so was extremely important for the self-esteem and quality of life of the PWMS. Information and service providers should therefore recognise this and enable people to participate as fully as possible in life and not focus only on information specific to MS.

Information provision plays a significant role in terms of PWMS' perception of the interaction between service provider, such as, the health service provider and themselves. The majority of PWMS want to be informed. Information seeking behaviour, however, will be affected by cognitive factors such as concentration and physical factors such as eyesight and mobility. Not all PWMS, however, want all the information that is of relevance to MS. This is because people experience different symptoms and also because some people are less motivated to seek or have information.

Information use is likely to be facilitated if information is provided in the context of emotional support and where possible in a positive manner – rather than only concentrating on the negative aspects of MS. For example, providing 'tips' and positive accounts of how people have dealt with a particular problem rather than listing possible problems would be useful.

### **Information needs of people with MS**

The information needs of PWMS can be categorised as: '***information about MS***' and '***information that helps people with MS interact with the world around them***':

- ◆ ***Information about MS.*** This included:
  - answers to questions about MS in general. This would include information about:
    - MS, a general explanation
    - MS research trials
    - Drug treatments
    - Symptoms, including: fatigue, balance and problems walking, bowel and bladder disturbances, problems with vision, cognitive problems such as memory and concentration

- Symptom treatment
  - Physiotherapy
  - Complementary therapy
  - Nutritional advice
  - Health and fitness
  - Emotional changes
- answers to questions about the PWMS' condition
    - specific symptoms experienced by the PWMS
    - prognosis
- ◆ **Information that helps PWMS interact with the outside world.** This included:
- Information about service providers
    - PWMS need information about the range of services that may be of help and also how to effectively contact, interact with, and get assistance from these services. These services include:
      - social services, Benefits Agency, health service, services for the disabled (blue badge, aids and appliances, home modification etc.), and voluntary organisations at national and local level. The names and addresses for all relevant organisations should be made available as well as information about the services they provide.
  - Information about MS and work and the possible implications of giving up work.
    - PWMS need information about their rights with regard to work as well as about giving up work and the likely implications, both financial and social.
    - PWMS need help identifying appropriate work.
    - Work is important to PWMS for reasons of self-esteem as well as for financial security.
  - Information about aids and appliances. Aids and appliances, as well as solving immediate problems also contribute significantly to the quality of life of the person with MS who has disabilities. These aids and appliances help them to participate in life and hence are important for self-esteem.
  - Information for the family
    - PWMS need information to help them communicate with their family and friends about MS and their condition.
  - Leisure activities
    - PWMS want to participate in recreational activities whether at home or on holiday. These activities may range from shopping to foreign travel. Many of these activities are severely restricted due the lack of facilities for the disabled. Information therefore needs to be

consistently provided on disabled facilities in places to which the PWMS wants to go.

### **Additional information provision**

The following information also needs to be made available:

- Information for the general public
  - The general public need to be better informed about MS in particular and disabilities in general.
- Information for service providers
  - Service providers, such as GPs, need to be better informed about MS and have access to information about MS and other services that may be of use to PWMS.
  - People who regularly work with PWMS, such as neurologists and MS specialist nurses, need to be trained about the information needs of PWMS and how to provide information in a way that is sensitive to the needs of the individual.

### **Information at diagnosis**

The time of diagnosis is obviously a very significant time for the PWMS. It is a time when PWMS need emotional and practical support. It has been shown that diagnosis without emotional and practical support is likely to lead to a negative experience by the PWMS. Information provision has improved dramatically over the last seven years but it is still inconsistent. At diagnosis there is therefore a need for:

- health professionals and service providers to be able to identify the information needs of the PWMS
- consistent information provision
- information that is provided in an emotionally supportive environment and
- information that is provided in a way that is sensitive to the emotional and practical needs of the PWMS (as previously stated not all people want the same or the same amount of information).

Information was required on all the categories of information suggested to the PWMS. However over 50% of the total number (2030) of respondents wanted information on the following categories of information at diagnosis:

- managing symptoms that they are experiencing
- possible drug treatments
- an indication of the course of the MS
- information about exercise
- information about the availability and role of the MS specialist nurse
- Information for the family
- Information on diet

One important source of information and emotional support was highlighted throughout the study: contact with other PWMS. Contact with other people with MS helped in many ways, including:

- tapping the knowledge of other people with MS, for example about a specific symptom or how to get access to a particular service;
- positive emotional support. Local MS Society branches and MS Therapy Centres played a key role, for many people, in helping to maintain a positive attitude to living with MS.

## **Recommendations**

### **Information at diagnosis**

- At diagnosis information should be made available about MS in general and the condition of the individual with PWMS. Information must be provided sensitively to the PWMS, however, and in an emotionally supportive environment.
- At diagnosis information should also be made available that helps the PWMS interact with the outside world, including:
  - ◆ Information for the family
  - ◆ Information about services and service providers
  - ◆ Information about local support and contacting other PWMS.

### **General information provision**

- Service providers, especially consultant neurologists and MS specialist nurses, should be aware of the information needs of PWMS and trained in the most effective way to satisfy these needs.
- Service providers need to be aware of the varied and changing nature of MS and that support needs to be provided over an extended period of time.
- An information service should be developed that enables permanent access, at any time, to the full range of information categories identified in this study, for
  - ◆ PWMS
  - ◆ The general public (families, friends etc.)
  - ◆ Service providers
- Information should be made available in a way that caters to the individual needs of the PWMS in terms of either the topic of concern or the situation which needs resolving.
- Information should be made available in an appropriate manner. This includes:
  - ◆ Providing information in, where possible, a positive fashion

- ◆ Providing information that helps people to take action
- ◆ Providing information in a way that motivates the PWMS to become informed and where appropriate act upon it
- ◆ Using the most effective means of communication, such as, face to face, paper leaflet etc.
- ◆ Taking into account the possible impact of MS on the cognitive and physical condition of the PWMS.

### **A template for information provision to PWMS**

To satisfy the information needs of PWMS and to assist service providers to help PWMS a 'one-stop' information service would be a possible solution. It is likely that such a service would be World Wide Web-based. Where appropriate, however, other means of communication should be used such as face-to-face or paper. Face-to-face communication is particularly important for dealing with personal and complex issues. A Web-based service could, nevertheless, be used to facilitate other forms of communication such as face-to-face via video, and leaflet generation. With regard to any means of communication the physical and cognitive needs of the user should be taken into account.

An effective information service for PWMS would have the following general characteristics:

- sensitive to the particular situation that the PWMS is trying to resolve;
- sensitive to the cognitive, physical and emotional condition of the PWMS;
- proactive, that is, actively disseminating information to PWMS who want information on specific topics, such as, MS research;
- enabling in terms of helping PWMS to inform themselves;
- allow the most appropriate form of information provision, for example, face to face for sensitive issues, peer to peer for information exchange and emotional support, leaflets (paper or electronic) for basic information, such as lists of useful organisations etc.

To satisfy the diverse information needs of PWMS as well as the demand for different format and modes of interaction it is recommended that for all topics, identified in this study, information should be made available in the following way:

- ◆ **Overview and detail.** PWMS require clear informative guidance on a range of issues provided by a trustworthy source. They also require choice. Providing an overview and detailed coverage of a topic would enable users to have a degree of choice over what they chose to read and how much information they accessed. The design of such sources of information would need to take into account the effect of both cognitive and physical barriers that may hinder information use by a PWMS.
- ◆ **Links to published literature.** PWMS want to be able to inform themselves. Increasingly, due to the opportunity to access professional material via the Web, lay people are using such material. Links, from the

'overview' and 'detail' information, should be made to additional information including:

- ◆ **Links to professional literature.** Articles would need to be reviewed, by the service provider, to ensure that they were based on good evidence (evaluation criteria are available).
- ◆ **Links to popular press,** for example, the national media and magazines. Again, referenced articles would need to be reviewed to ensure that they were based on good evidence.
- ◆ **Video and email link to an expert with regard to specific or general topics.** The need for face-to-face discussion, especially with regard to sensitive personal issues, with experts is difficult because of limited resources. Interactive video communication between the expert and the inquirer could, however, help. Email without video would provide the opportunity for one-to-one discussion with an expert but would of course lose the face-to-face component.
- ◆ **Links to appropriate topic specific or general chat rooms and/or discussion lists.** Contact with other PWMS was seen to be extremely important for most PWMS. The provision of subject specific and general chat rooms and or discussion lists would enable people to discuss issues and share information with other people with MS. Experts could also be involved in these discussions. This method of information access would mean that information is likely to be presented in terms of real life experiences and hence would be easy to relate to and trust. It would also help resolve the feeling of isolation commonly experienced by people with MS. Moderation of these discussions would need to take place to ensure the quality of information.
- ◆ **Link to positive accounts and 'tips' from people with MS** who have had to deal with a similar topic or situation. It was evident in the focus groups that tips from other people were particularly useful because the information provided was:
  - specific and highly relevant to the query
  - provided by someone who had experienced a similar situation and was likely to be trusted
  - communicated in a language that PWMS could understand and relate to
  - a source of positive information.

### ***Further research***

1. Test the impact of information provision as recommended in this report. This would involve creating information (outline, detail, links to literature, tips) and the supporting services (interactive video, chat rooms/discussion lists) on a limited range of topics. One could choose those needed at diagnosis or those generally considered most

important. This would be followed by a pilot study of the impact on the use and usefulness of this experiment to PWMS.

2. Investigate the influence of cognitive and physical factors on information use by PWMS. It was found that cognitive and physical factors did have an impact on information use, particularly in terms of fatigue, concentration and mobility. Exactly how these factors affect the demand for and use of information and how these factors should be taken into account with regard to information provision is unclear and requires further investigation.
3. Investigate the motivational factors associated with information use and non-use. It was found that there were significant differences in people's desire to be informed and the effort they were willing to make to find relevant information. Again it is unclear what is the source of these differences and whether these differences have implications for how information is provided.

It is likely that an investigation of these themes would lead to knowledge that would be useful to people who provide information to people in general as well as PWMS.

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## Appendix 1: Focus Group Information Sheet

### INFORMATION SHEET FOR FOCUS GROUPS

Thank you for expressing an interest in taking part in the Information Needs of People with MS study funded by the MS Trust and undertaken by Loughborough University.

The aim of the study is to thoroughly investigate the information needs of people with MS. The views of people with MS will be gathered by running focus groups in eleven therapy centres around the country and later by the distribution of several thousand questionnaires.

The focus group will last one and a half hours. First of all you will be asked to spend fifteen minutes thinking about and identifying situations you have had to deal with associated with having MS. You will then be gathered in a group of about ten people with MS to discuss these situations. The purpose will be to identify critical situations and the information you needed to manage these situations and any problems you may have had getting the right information in a way that suits. Each focus group will be devoted to either people who are newly diagnosed, or those who do not regularly use a wheelchair or those that do.

This research will result in recommendations and guidelines for information and knowledge provision to people with MS. These recommendations will influence the development of information services by the MS Trust and will also feed into national health and social welfare strategies.

If you do take part you will help to make sure that the results of the study truly reflect the information needs of people with multiple sclerosis.



## Appendix 2: Full list of topics raised in focus groups

### Access and Transport

#### Access to New London Theatre

- Access to places
- Airlines are very helpful
- Bad experience when travelling by train
- Driving
- Failure to recognise the implications of disability by most people
- How to get a wheelchair  
I was unable to get to my car and I had to ask a stranger (a man) to help me to my car.
- Inability of able-bodied people to recognise needs of disabled people for access to disabled toilets
- Inaccessibility of homes, offices, shops, etc
- Keeping myself independent and mobile (car)
- Loading wheelchair into and out of car
- Looking for dropped curbs when in scooter or wheelchair
- Missing out on social events because of bad wheelchair access
- Parking
- People's reaction to wheelchair
- Problems with shopping
- Radar key, disabled toilets, some poorly designed (door won't shut behind you)
- Swimming access
- The tube system is totally unusable
- Transport and Mobility
- Trying to find disabled parking space
- Why are disabled departments upstairs and in the middle of town with no parking?

### Aids & Appliances

- Equipment - availability, funds to get it
- Getting form for disabled badge

## Balance & Walking Problems

- Always having to check for steps, etc
- Cannot walk the dog as far as I would like, especially in winter
- Cleaning windows
- Climbing stairs
- Falling – frightening, avoiding
- Getting up when on ground
- Legs giving out for no reason
- Not being able to walk without staggering
- People look at you when you walk and they think you are drunk.
- Putting socks on.
- Spasms in legs
- Stairs, steps without a rail
- Taking a shower
- To carry more than one thing at a time is impossible
- Walking lose balance , get tired
- Walking in the dark, on snow, on stairs

## Bladder & Bowel disturbances

- Loss of control over bladder and bowels
- Urination problems – catheterised
- Water retention

## Benefits & Entitlements

- Getting social services to understand when forms have to be filled out
- Help filling in forms, they are a minefield
- How do you find the right carer?
- Newly diagnosed and then made redundant, who to ask for info on benefits
- Social worker helped after my daughter got in touch with them

## Emotional Changes

- Coming to terms with MS
- Depression
- Fatigue and depression, how to deal with it?
- Firstly diagnosed by post, was devastated, did not know much about MS at all
- Frustration

## General Information about MS

- Consultant very loath to say what I had
- Information from doctors, what help is available
- You have MS there is no cure so goodbye
- Diagnosed, told to go away and forget about it
- Diagnosis in South Africa not accepted in UK – Dr very scathing
- Diagnosis of neuritis, not MS, no one else had neuritis, no information for 13 years then told had MS.
- Didn't know what to expect
- Difficulty in describing illness for Drs, Social Services to understand
- Difficulty relating to consultant, not prepared to discuss reality
- Feeling relieved at getting the diagnosis of MS rather than I was going mad
- Limited information on MS in general
- More information at diagnosis how to live with whatever, how to look after yourself. E.g. diet.
- MRI scans taken in South Africa not available in Leicester
- No diagnosis until I read about it in an old medical dictionary in the hospital day room.
- Specialist told wife but not me, she told me after 8 years
- System should be able to provide support from start, with total advice
- There wasn't a body or organisation that dealt with a combination of problems i.e. financial, mobility, house improvements
- Was disappointed not to have access to an MS specialised nurse on diagnosis
- When first diagnosed not being able to receive true information, everyone being frightened to say or admit to us what MS is or means, what the future held

## General Symptom Management

- Being very tired, exhausted
- Cannot get up ladders to clean windows
- Child rearing issues, fatigue, embarrassment, producing meals
- Coping with relapses
- Curbing expectations
- Difficulty in turning taps, opening jars, lifting kettle
- Difficulty sleeping
- Fear of Unknown (Future)
- Feeling of abandonment by NHS, indifference by system that should care
- Getting into the NHS system

- GP does not offer reassurance, doesn't seem to care greatly how I cope
- Having to chase Dr. to get tests done
- How do you deal with other people's misconceptions
- How do you get to see a consultant
- NHS seem unable to cope with people who have an incurable condition
- No information from NHS
- No-one to talk to when first diagnosed
- Once diagnosed dismissed from hospital and more or less told get on with it.
- People cannot realise that I want to try to do jobs myself rather than as if it is wrong – I have had a go
- Things in general have to be forward planned
- Total lack of continuous care and follow up.
- Trouble getting clothes to suit disability
- What next, unknown
- How helpful people can be whatever the situation
- Once diagnosed with MS all health problems are put down to the MS
- Swallowing

### Home Modifications

- Acceptance of needing home-care
- Coping in the house, bathing, stairs
- Housing

### Information for Family and Friends

- How to tell friends, family, work
- Husband and I spilt up and are now divorced, having a child caught in the middle
- Making friends
- Meeting new friends who are now best friends
- Other people not knowing what MS is
- Personal relationships

### Leisure Activities and Holidays

- I was very fit and played many sports before MS. It took me around 3-4 years to overcome the problems. It was - for me entirely psychological to do this.
- Fitness. Gyms requiring doctors signature, personal liability form
- Holidays - problems finding disabled friendly facilities
- More free time to develop leisure time

### Memory Problems

- Concentration
- Mental problems that incapacity produces

### New and Unusual Symptoms

- Fever – how to deal with it, be aware of
- Signature for my switch card is deteriorating, what happens in shops?
- Trigeminal neuralgia, affecting speech and swallowing control
- 

### Nutritional Advice

- Does diet really make a difference
- Following gluten free diet really helped

### Organisation Addresses

- No-one told me about MS Centre, found out by chance

### Physiotherapy

- No Physiotherapist to deal with needs of you personally
- Not enough Physiotherapy available
- Physiotherapy at home would be good

### Research

- Lack of information on research

### Stress

- Divorce – stress
- Help - horrible to ask
- Husband leaving – stress
- Separation from marital home

### Visual Problems

- Eyesight weakness

## Working and MS

- Accused of having a fit at work – no help from union
- Had to give up work
- Medical retirement
- Not having a language to explain how I was feeling to colleagues at work.  
Difficult to explain the odd feelings.
- What do you tell your employers
- Work, money, insurance, etc

## Other Comments

- Lack of contribution from NHS/Government to charities like MS Centre
- Positive attitude of young people to disabled people's requirements

## **Appendix 3: Questionnaire**



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## The Information Needs of People with Multiple Sclerosis

Please tick the appropriate boxes.

All information will be treated in the strictest confidence.

Please tick if someone filled this questionnaire in on your behalf

### Section 1. Personal Information

1.1 Are you: Male  Female  1.2 Postcode: \_\_\_\_\_

1.3 What is your age? 16 or under  17-19  20-29  30-39   
40-49  50-59  60-64  65-69  70-74  75+

1.4 Approximate year of first symptoms: \_\_\_\_\_

1.5 Approximate year of definite diagnosis of MS: \_\_\_\_\_

Please tick if you have not received a definite diagnosis

1.6 Current employment status:

Full-time	<input type="checkbox"/>	Seeking work	<input type="checkbox"/>
Part-time	<input type="checkbox"/>	Permanently unable to work	<input type="checkbox"/>
Retired	<input type="checkbox"/>	Full time education	<input type="checkbox"/>
Voluntary	<input type="checkbox"/>		

Other: \_\_\_\_\_

1.7 At any time has your MS affected your employment status?

Yes  No

**1.8 Please rate YOUR symptoms and disabilities overall using this scale. Circle the number which would represent your symptoms. (0 = no symptoms 10= severe symptoms)**

**01    2    3    4    5    6    7    8    9    10**

<b>Section 2. Time of Diagnosis</b>
-------------------------------------

**2.1 WHO did YOU receive your diagnosis from? (Tick one only)**

Consultant Neurologist	<input type="checkbox"/>	Nurse	<input type="checkbox"/>
Other hospital doctor	<input type="checkbox"/>	GP	<input type="checkbox"/>
Relative	<input type="checkbox"/>	Have not had a diagnosis	<input type="checkbox"/>

(Please go to Qs. 3.1)

Other: \_\_\_\_\_

**2.2 WHAT information were YOU given at the time of your diagnosis? (Tick all that apply)**

Possible physical symptoms	<input type="checkbox"/>	Possible psychological symptoms	<input type="checkbox"/>
Information on diet	<input type="checkbox"/>	Counselling	<input type="checkbox"/>
Information on exercise	<input type="checkbox"/>	MS specialist nurse	<input type="checkbox"/>
Possible drug treatments	<input type="checkbox"/>	Driving	<input type="checkbox"/>
Managing symptoms	<input type="checkbox"/>	Organisation addresses	<input type="checkbox"/>
Indication of disease course	<input type="checkbox"/>	Contact for group of newly diagnosed	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>	Benefits and entitlements	<input type="checkbox"/>
Alternative therapies	<input type="checkbox"/>	Work related information	<input type="checkbox"/>
Occupational therapy	<input type="checkbox"/>	Information for family	<input type="checkbox"/>

**No information was given**

Other: \_\_\_\_\_

**2.3 In what areas would YOU have LIKED to be given information at the time of your diagnosis? (Tick all that apply)**

- |                              |                          |                                      |                          |
|------------------------------|--------------------------|--------------------------------------|--------------------------|
| Possible physical symptoms   | <input type="checkbox"/> | Possible psychological symptoms      | <input type="checkbox"/> |
| Information on diet          | <input type="checkbox"/> | Counselling                          | <input type="checkbox"/> |
| Information on exercise      | <input type="checkbox"/> | MS specialist nurse                  | <input type="checkbox"/> |
| Possible drug treatments     | <input type="checkbox"/> | Driving                              | <input type="checkbox"/> |
| Managing symptoms            | <input type="checkbox"/> | Organisation addresses               | <input type="checkbox"/> |
| Indication of disease course | <input type="checkbox"/> | Contact for group of newly diagnosed | <input type="checkbox"/> |
| Physiotherapy                | <input type="checkbox"/> | Benefits and entitlements            | <input type="checkbox"/> |
| Alternative therapies        | <input type="checkbox"/> | Work related information             | <input type="checkbox"/> |
| Occupational therapy         | <input type="checkbox"/> | Information for family               | <input type="checkbox"/> |

Other: \_\_\_\_\_

**Section 3. Finding Information on MS**

**3.1 WHO do YOU GO TO for useful information on MS? (Tick all that apply)**

- |                        |                          |                           |                          |
|------------------------|--------------------------|---------------------------|--------------------------|
| Alternative Therapist  | <input type="checkbox"/> | MS Society (Head office)  | <input type="checkbox"/> |
| Benefits Agency        | <input type="checkbox"/> | MS Society (Local branch) | <input type="checkbox"/> |
| Carer                  | <input type="checkbox"/> | MS Trust                  | <input type="checkbox"/> |
| Citizens Advice Bureau | <input type="checkbox"/> | Neurologist               | <input type="checkbox"/> |
| Dentist                | <input type="checkbox"/> | Other local branch        | <input type="checkbox"/> |
| Dietician              | <input type="checkbox"/> | Pharmacist                | <input type="checkbox"/> |
| Family                 | <input type="checkbox"/> | Physiotherapist           | <input type="checkbox"/> |
| Friends                | <input type="checkbox"/> | Other people with MS      | <input type="checkbox"/> |
| GP                     | <input type="checkbox"/> | Social Services           | <input type="checkbox"/> |
| Library                | <input type="checkbox"/> | MS Therapy Centre         | <input type="checkbox"/> |
| MS specialist nurse    | <input type="checkbox"/> |                           |                          |

Other: \_\_\_\_\_

**3.2 How DIFFICULT has it been for YOU to find out about the following:  
(Please tick ONE box per line)**

	<b>Very difficult</b>	<b>Difficult</b>	<b>Slightly Difficult</b>	<b>Not at all difficult</b>	<b>Not Needed</b>
Access & Transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Access to MS research trials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aids & appliances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary & alternative therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Balance, problems walking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Benefits and entitlement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bowel and bladder disturbances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drug treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General Information about MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General symptom management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home modifications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information for family/friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure Activities & Holidays	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**How DIFFICULT has it been for YOU to find out about the following:  
(Please tick ONE box per line)**

	<b>Very difficult</b>	<b>Difficult</b>	<b>Slightly Difficult</b>	<b>Not at all difficult</b>	<b>Not Needed</b>
Memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New and unusual symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritional advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organisation addresses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Visual problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Working and MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section 4. Being given Information on MS**

**4.1 In what WAY would YOU PREFER information on MS to be provided to you? (Please tick ONE box per line)**

	<i>Leaflet</i>	<i>Book</i>	<i>Video</i>	<i>CD-Rom</i>	<i>Magazine</i>	<i>Newsletter</i>	<i>Audio Casette</i>	<i>E-mail</i>	<i>Face-to-Face</i>	<i>Over telephone</i>	<i>Internet</i>
Access & Transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Access to MS research trials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aids & appliances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary & alternative therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Balance, problems walking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Benefits & entitlements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bowel & bladder disturbances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drug treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General Information about MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**In what WAY would YOU PREFER information on MS to be provided to you? (Please tick ONE box per line)**

	<i>Leaflet</i>	<i>Book</i>	<i>Video</i>	<i>CD-Rom</i>	<i>Magazine</i>	<i>Newsletter</i>	<i>Audio Cassette</i>	<i>E-mail</i>	<i>Face-to- Face</i>	<i>Over telephone</i>	<i>Internet</i>
General symptom management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home modifications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information for family/friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure Activities & Holidays	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New and unusual symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritional advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organisation addresses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**In what WAY would YOU PREFER information on MS to be provided to you? (Please tick ONE box per line)**

	<i>Leaflet</i>	<i>Book</i>	<i>Video</i>	<i>CD-Rom</i>	<i>Magazine</i>	<i>Newsletter</i>	<i>Audio Cassette</i>	<i>E-mail</i>	<i>Face-to-Face</i>	<i>Over telephone</i>	<i>Internet</i>
Visual problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Working and MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**4.2 How IMPORTANT is it for YOU to have information on the following: (Please tick ONE box per line)**

	Unimportant	Not very Important	Important	Very Important
Access & Transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Access to MS research trials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aids & appliances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Complementary & alternative therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Balance, problems walking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Benefits & entitlements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bowel & bladder disturbances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drug treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**How IMPORTANT is it for YOU to have information on the following:  
(Please tick ONE box per line)**

	Unimportant	Not very Important	Important	Very Important
General Information about MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General symptom management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home modifications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information for family/friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure Activities & Holidays	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New and unusual symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritional advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organisation addresses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Visual problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Working and MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.3 Does your MS affect how you find information? Yes  No

If yes, how? (Please tick all that apply)

Sight  Dexterity  Memory

Mobility  Fatigue  Concentration

Other: \_\_\_\_\_

**Section 5. Information and You - (OPTIONAL)**

5. Give one example of when you got information that made a positive difference to your life.

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**OPTIONAL:**

If you have any tips to give to someone else with MS please write them below:

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**OPTIONAL:**

**I would like to be placed on the MS Trust mailing list**

**I am willing to be involved in further research about information for people with MS**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Postcode: \_\_\_\_\_

E-mail: \_\_\_\_\_

**THANK YOU  
PLEASE RETURN IN THE PRE-PAID ENVELOPE PROVIDED**

**Data Protection:**

The Multiple Sclerosis Trust will use information supplied by you to keep you informed about the work of the Trust. If you have any query about the information the Trust holds and the use they make of it please contact the Trust.

The Department of Information Science, Loughborough University will use information supplied by you to help analyse current data and also to conduct future research into the need for and use of information by people with MS. Names and addresses of participants will not be disclosed by either the MS Trust or the Department of Information Science, Loughborough University to other organisations.

## Appendix 4: Questionnaire Information Sheet



### **The Information Needs of People with Multiple Sclerosis Questionnaire**

Thank you for expressing an interest in taking part in the Information Needs of People with MS study.

The aim of the project is to produce recommendations and guidelines on the provision of information and knowledge to people with MS. These will be based upon the experiences of people who are living with MS today.

Taking part in the study will involve completing the enclosed questionnaire on information provision for people with MS. It asks for your views on lots of topics surrounding getting information on MS.

All the information that you give throughout the project will be kept in the strictest confidence.

To complete the questionnaire all you need to do is tick the appropriate boxes that reflect your own thoughts, experiences or opinions. Some of the questions ask you to think back to when you were diagnosed and others want your opinion at the present time. Please read the questions carefully to make sure you are giving the correct type of answer.

If you have problems with your sight or if you have difficulty writing someone can complete the questionnaire for you. If they do please make sure they tick the box at the top of the first page that lets us know someone other than you filled in the questionnaire.

Please be as honest as you can when completing the questionnaire. If you cannot answer a question just leave it blank and go on to the next question.

Once you have completed the questionnaire please return it in the pre-paid envelope provided.

Thank you

## **APPENDIX 5: List of Information Needs Topics**

1. Access & Transport
2. Access to MS research trials
3. Aids & appliances
4. Complementary & alternative therapies
5. Balance, problems walking
6. Benefits & entitlements
7. Bowel & bladder disturbances
8. Drug treatments
9. Emotional changes
10. General Information about MS
11. General symptom management
12. Home modifications
13. Information for family/friends
14. Leisure Activities & Holidays
15. Memory problems
16. New and unusual symptoms
17. Nutritional advice
18. Occupational therapy
19. Organisation addresses
20. Physiotherapy
21. Research
22. Stress
23. Visual problems
24. Working and MS