

# The information needs and preferences of people newly diagnosed with MS

## Report of Principal Aim –

To explore the information needs and preferences of people who have been newly diagnosed with MS

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## **Executive summary**

### **Background**

This research focuses on the information needs and preferences of people who have been newly diagnosed with MS as well as the views of their families. For the purposes of this project, “newly diagnosed” was taken to include people who had received a diagnosis of MS within the past 5 years. This period of time takes account of the varied trajectories of the disease and the mean time to commencement of disease modifying therapies.

### **Objective**

To explore the information needs and preferences of people who have been newly diagnosed with MS.

### **Method**

A range of qualitative methods were used to explore the information needs and preferences of people newly diagnosed with MS. These included:

- 34 telephone interviews
- 5 in-depth (face-to-face) interviews
- 4 focus groups
- 25 email submissions from people not selected for interviews or focus groups

The main means of publicising the call for participants were an article in Open Door, the MS Trust newsletter, and information on the MST website. These approaches generated a very large response (approximately 180 people), mostly from people who had read Open Door. A further cohort of people came forward later to volunteer for specific focus groups, as a result of a range of recruitment strategies.

Analysis was based on the Framework Method. More information about that and other aspects of the methodology are provided in Appendix 1.

### **Results**

A number of different themes arose from the research. These were:

#### The patient journey: uncertainty and change

People with long term conditions are often described as being on a journey. For people with MS, that journey is sometimes quite uncertain as it is not possible to predict, with accuracy, how their MS might affect them, or the rate at which symptoms might develop or change. People reported fluctuations in their appetite for information, and different kinds of information were important at different times.

### Trust and authenticity

People with MS and their families want to know that the information they seek and receive is from a trusted source and is reliable and authentic. The MS Trust is seen as a trusted source of high quality information.

### Personalisation

Information should be to be tailored towards individual needs.

### Format of information

Many people were happy to receive information in a variety of formats, but within that there were often marked preferences. Many people see the internet as their natural source for information, but printed information, and information imparted by a known and trusted person remain important to many.

### Support

Some people needed support in order for them to be able to make use of information.

### Co-ordination of information provision

Both healthcare providers and professionals and voluntary organisations have a major role to play in providing information to people who are newly diagnosed with MS and their families. They can and should also signpost people towards other sources of information that may be useful.

### Empowerment

Many people newly diagnosed with MS are extremely motivated to look after themselves and care for their own health and in many cases to take an active role in obtaining information to meet their own needs.

## **Implications**

The report identifies implications of the key themes that emerged from the research. While MST is already meeting many of the information needs and preferences of people newly diagnosed with MS and their families, it may be able to develop further its own information services and materials in line with these themes and their associated implications. There are also some areas that would benefit from further exploration and from work in partnership with others.

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## **1. About the project**

### **1.1. Terms of reference and scope**

In December 2011, the MS Trust (MST) commissioned a consortium of three independent researchers, Ros Levenson, Mercy Jeyasingham and Sarah Smith, to carry out a research and evaluation project to explore the information needs and preferences of people who are newly diagnosed with multiple sclerosis (MS). For the purposes of this project, “newly diagnosed” was taken to include people who had received a diagnosis of MS within the past 5 years. This period of time takes account of the varied trajectories of the disease and the mean time to commencement of disease modifying therapies.

The Project had two separate, but related, aims.

*Principal Aim:*

*To explore the information needs and preferences of people who have been newly diagnosed with MS.*

*Secondary aim:*

*In the light of the information needs and preferences of people newly diagnosed with MS that have been identified, to evaluate current MST resources for people who are newly diagnosed with MS.*

A report of the findings of the Principal Aim are presented here. It is intended for the MST, as well as for a wider audience including people with MS and their families, and health care professionals and information providers working with people who are newly diagnosed with MS. A report of the findings of the secondary aim will be presented to the MST for its own use in planning the development of a new work programme focussing on those individuals who are newly diagnosed with MS.

### **1.2. Timetable**

The project took place in a short period of time, commencing in January 2012. Fieldwork commenced in February, a draft report was presented in May and a final report in June 2012.

## **2. Summary of methods used for principal aim**

A range of qualitative methods were used to explore the information needs and preferences of people newly diagnosed with MS. These included:

- 34 telephone interviews
- 5 in-depth (face-to-face) interviews
- 4 focus groups

25 email submissions from people not selected for interviews or focus groups

These methods and the recruitment process are described in detail in Appendix 1.

### **3. Findings of principal aim**

In this part of the report, we set out the findings from all parts of the fieldwork for the principal aim of the project. We look at how information needs and preferences change over time, and how they differ between individuals as well as for people with MS and those close to them. We also look at preferences in relation to how people choose to obtain information and the formats in which they like to receive it. We also look at what people thought about the MS Trust's Information Service, if they had used it, and we have drawn together material on possible gaps in information for newly diagnosed people and their families.

#### **3.1. The changing nature of information needs and preferences**

##### Concept of the patient journey

Information needs and preferences vary a great deal from person to person, even within the group of people who may be considered newly diagnosed. Variations reflect the different needs and priorities of individuals, but also each person may find that his or her own needs vary as time passes. The concept of the "patient journey" is usually used in relation to clinical process redesign, including all the sequential steps in providing a patient's clinical care (Medical Journal of Australia, 2008). It is also used analogously as a convenient short-hand to capture the process by which a person's experiences and needs change as their condition changes and their ways of coming to terms with it develop. This can link to changing information needs as follows:

*I was originally told about the diagnosis 16 months ago and I had a standard reaction and said "yes, OK" and ignored it. Then I couldn't ignore it and it came to a head a couple of months ago. (Woman, age 36-45, with relapsing remitting MS)*

##### Information before diagnosis

For some people, the journey begins well before a diagnosis of MS is made. People may face lengthy investigations before diagnosis. Some people wish to have information at the earliest possible stages, both about investigations and about medical conditions (including MS) that may be diagnosed as a result. Others prefer to know as little as possible until the diagnosis is settled:

*People are different. My opinion is you're sometimes better not*

*knowing. I have a friend with MS and he just wanted to know everything. My first episode was 14 years ago but was undiagnosed. That was better as I could live my life in complete ignorance in that time. (Woman, age 46-55, with relapsing remitting MS)*

*When it was a maybe I wanted to know what it entailed and worst case scenarios, but I never wanted to dig any further. (Woman, age 26-35, with relapsing remitting MS)*

The need for appropriate information is compounded by the likelihood that some people will be more ready to accept a possible diagnosis of MS than others. As one woman explained:

*I was unable at that stage to face that I had MS. I didn't want to be part of the MS club yet. I wanted to know what they were looking for and what they were going to find. I wanted to know what's going to happen and what else it could be. (Woman, age 36-45, with relapsing remitting MS)*

While sensitivity to individual needs is essential at all times, it is particularly vital at the pre-diagnosis stage, as people may be in shock, unwell and without appropriate advice and support. Nor do they necessarily know what questions to ask:

*I had an MRI in the December the year before I was diagnosed and was then sent for a lumbar puncture, the neurologist said it was possibly MS, so I wanted so much information before I got diagnosed. As it was, I went with my partner and we were green. We sat there thinking: what do I ask? (Woman, age 26-35, with relapsing remitting MS)*

People also said that their knowledge of MS at the pre-diagnosis stage was often sketchy, and their main fear was that disabilities would develop quickly, particularly to the point of needing to use a wheelchair.

*I did not know anything about MS at all. I needed to be reassured that it [all the symptoms] weren't going to happen in a period of months. Your first thoughts are of wheelchairs. I needed to be reassured that that wasn't going to be the case. (Woman, age 18-25, with relapsing remitting MS)*

One person would have liked a web page for those being diagnosed. She would have particularly liked an interactive site that would allow her to input information about herself and to filter the information she needed to receive.

### Information needs and preferences soon after diagnosis

Although the information needs and preferences of a few people soon after

diagnosis had much in common with later needs and preferences, the great majority of people recalled a period of shock and in some cases, denial. This impacted heavily on what they wanted to know and their ability to seek out, hear and process information. The following comments are typical:

*Actually I couldn't wait to get out of the room, to go somewhere quiet and think about what he had said. (Woman, age 46-55, with primary progressive MS)*

*I can't remember what information I got. I can't remember anything about it. (Focus group participant, woman age 46-55, with relapsing remitting MS)*

*I needed to know where I stood in life. It happened very quickly. I can't get my head round how it happened. I'd like to know what the hell is happening. (Woman, age 26-35, with relapsing remitting MS)*  
*It was a bolt out of the blue. I don't know what I wanted. Someone to speak to in due course. I was in denial at first. (Man, age 36-45, with relapsing remitting MS)*

The stage immediately after diagnosis was often a stage at which people wanted to know "why me?" Some hoped for information that would tell them whether they had done something to cause the MS (or to reassure them that they had not). Others wanted to understand why they had got MS when no-one else in the family had it.

*I wanted to know how did I get it, as no-one in my family has it. Why me? ... I've come to terms with it now and there are good days and bad days but I'm still racking my brains how I've ended up with it. (Man, age 26-35 with relapsing remitting MS)*

*I just wanted to know why I had it. I eat healthily, I do sport. (Woman, age 26-35, with relapsing remitting MS)*

Often, people's needs for information centred on the need for reassurance about the future.

*I didn't know what I wanted. I wanted someone to tell me it would be fine and that it would go away! (Woman, age 36-45, with relapsing remitting MS)*

*What am I going to be like in a year's time? When am I going to be in a wheelchair? (Focus group participant, woman, age 36-45, with relapsing remitting MS)*

Frequently, people with MS were perturbed by the lack of certainty about what might happen in the course of their MS. Although they came to understand that MS can vary immensely from person to person, that

knowledge was sometimes construed, at first, as unhelpful as it did not address their need to know what would happen to them as individuals.

One man commented that, at diagnosis, it is not really a matter of 'information' as such. He felt that there was possibly too much information, but what was lacking was contact with someone else with MS to relate to. A small number of people recalled being given information that they did not read at the time and in some instances, had still not read.

*I picked up information but I have never read it to this day. ... I did not decide not to read the information – I just never did. I wasn't in the right place – and I had a lack of cognitive ability. (Woman, age 46-55, with secondary progressive MS)*

*I picked up the brochures from out patients..., but I did not read them. I didn't read as I couldn't cognate it (Woman, age 46-55, with secondary progressive MS)*

Others noted that their desire for information fluctuated. Sometimes they wanted to know as much as possible and at other times they preferred to shield themselves from information. Generally, people wanted information in small chunks to help them understand the basics about MS and to enable conversations if they chose, with family and friends.

A minority of people said they had wanted to know "everything" at first, although they had not always sustained that position:

*When I was diagnosed I just wanted to find out as much as possible – everything! We're all very much in control of our lives, but then you can't be. I wanted to know what type of MS it was, how it would develop and I wanted to know if I'm going into secondary progressive. (Woman, age 36-45, with relapsing remitting MS)*

*At the beginning I wanted to know everything. Now I go back to it for what I need. But initially I did scare myself stupid while I was in hospital. (Woman, age 26-35, with relapsing remitting MS)*

Some people recalled that they had scared themselves by seeking out too much information too soon. Sometimes this was against the advice of healthcare professionals. Some people felt that if they had had more guidance on where to look for information they might have been less likely to search indiscriminately.

After an initial period of shock, people wanted information on a range of topics, soon after diagnosis. These included:

- How people with MS approach the emotional aspects of having MS
- Could they have children?

- Would their children develop MS?
- Questions about driving
- Questions about the ability to work
- Local information, especially about local support
- Understanding symptoms and identifying relapses
- Research into MS and developing therapies

### Information needs and preferences as time goes on

As time went on, individual variations in needs and preferences were still common, although there was a general trend towards wanting more information, and more specific information. Often people had insight into this and described their journey through various stages. More than one person explicitly referred to having gone through five stages of grief and a period of mourning in relation to their MS.

*I think I went through a grieving process –for the life I would have had. (Focus group participant, woman age 36-45, with relapsing remitting MS)*

As with the immediate post-diagnosis period, there was wide variation in how much information people wished to have, with people emphasising that they still chose to restrict the amount of information to which they were exposed.

*Being a health professional, I surprised myself as I did not want to know much. (Woman, age 46-55, with relapsing remitting MS)*

*I didn't want to go looking for things that may never happen. (Woman, age 46-55, with relapsing remitting MS)*

Sometimes, an initial flurry of information-seeking gave way to another phase.

*I did an initial blitz then I thought this is how I'm going to live my life and because I can still do things I just get on with everyday life. (Man, age 46-55, with secondary progressive MS)*

*After the initial stage of reading anything about MS ..., I went through a stage where I did not want to read anything. Until you find something of interest again, like to CCSVI [Chronic cerebro-spinal venous insufficiency] of late, so yes, it does change. (Man, age 46-55, with secondary progressive MS)*

For some people, information needs developed in response to their experience of MS- related symptoms, such as fatigue or muscle spasms. Others found that this was the stage at which practical issues, such as driving, insurance and employment, came to the forefront. As time went on, people often also wanted to know more about disease management options.

While many wanted information on medical management options, there was also considerable appetite for other ways of managing MS, which we will discuss in more detail later.

*I most wanted to know 'how bad is this going to get?' - but no-one can answer that question. So the second best thing was to know what I could do to help myself, for example, lifestyle changes. (Email, woman, age 26-35, with relapsing remitting MS)*

Some people reported that they became more aware of their need for information on personal, social, emotional and psychological issues, communication about MS with others and on sources of support.

*Now I am more focused on the future and on how people can help me now. Before it was about what is happening to my body. (Woman, age 36-45, with relapsing remitting MS)*

*What I wanted most was information on sex and information on depression. (Woman, age 46-55, with secondary progressive MS)*

As time passed, people sometimes wanted more information about research into MS.

*I find links to articles and research in the press very useful. It makes me feel I'm up to date. I hate it when I hear about it from others. I like to know what's going on. (Woman, age 36-45, with relapsing remitting MS)*

*Our needs have developed and changed – we want to keep up with things like stem cell and other developments – it gives her hope. (Man, age 56+, husband of woman with primary progressive MS)*

#### How the experience of diagnosis impacts on the quest for information

While many variables impact on people's information needs and preferences, it appears that the individual's experience of diagnosis with MS may be one of the more significant issues. We heard of experiences that ranged from excellent to alarmingly poor, and these were often recalled in great detail. One person described learning about her diagnosis from a copy of a letter sent to her GP by her neurologist. Another said she felt "labelled and left". Comments included:

*I was diagnosed by the neurologist who was amazing – the best guy to break bad news. He said it is the best time to be diagnosed as lots is happening – a very positive outlook. (Woman, age 26-35, with relapsing remitting MS)*

*My experience of being diagnosed was one of clinical excellence followed by a deafening silence, leaving me bewildered and knowing*

*nothing about what I needed to do to maximise my abilities. (Email, man, age 56+, with secondary progressive MS)*

*Neurologist not only lost my appointment so I was shoved into a ten minute slot but was obnoxious, abrupt and downright rude, bombastic and uncaring. ... We both left the Neurologist's consulting room in shock. (Email, woman, age 46-55, with primary progressive MS)*

For some people, diagnosis had been a gradual process, with their own suspicions preceding a formal diagnosis. In that period, people had sometimes started their own quest for information.

*For some reason I thought it was transverse myelitis .... and there was a conference on TM that I was able to attend and they explained about how it works and I got a lot of information for myself, and MS is not so very different. (Man, age 36-45, with relapsing remitting MS)*

*I first presented with symptoms 6 or 7 years ago and there was a possible MS diagnosis then, so I looked into things a bit myself between then and now. (Woman, age 26-35, with relapsing remitting MS)*

Others had chosen not to begin to seek information before a confirmed diagnosis. One person observed that she would have liked to prepare her questions, and if she had known more about the diagnosis she would have known what to ask.

Several people had acquired information from family members with MS, prior to their own diagnosis.

*My mum has MS so I was aware of therapy centres, but my understanding from mum, what she'd been told for 25 years, was there was nothing you could do about it. (Man, age 46-55, with secondary progressive MS)*

*It took a year to get a diagnosis by which time I had all the information I needed. And my mother had had MS. I had eye problems and backache issues and in my heart of hearts I knew I had MS. (Woman, age 36-45, with relapsing remitting MS)*

When diagnoses were not given clearly and sensitively, people's ability to take in information may have been adversely affected.

*The diagnosis part was unsatisfactory. Rather than being told that she had MS, we were left to join the dots ourselves. (Man, age 46-55, husband of woman with relapsing remitting MS)*

*My cognition had slowed over working things out. I came out feeling*

*dissatisfied that I had not understood what was going on. (Woman, age 46-55, with secondary progressive MS)*

*The guy at A&E said matter of factly “ has anyone in the family got MS?” and I fixated on that and went down hill from there. .... When she was diagnosed, it got worse. Minutes after she was told she had MS they tried to explain, but no way we could take it in. It is still difficult to talk or read about it. (Man, age 36-45, father of woman with relapsing remitting MS)*

### Whether diagnosis with MS alters information seeking behaviour

As we have seen, receiving an actual diagnosis is a very important stage and can influence information-seeking behaviour and the appetite for information. But it is not simply the way in which the diagnosis is given that has an effect. It is also the new certainty about diagnosis, sometimes after a long period of uncertainty, that affects people.

*I only started going on my information trawl when I got the final diagnosis. (Man, age 46-55, with secondary progressive MS)*

*Even though I knew it was likely, I hadn't looked into it. Once I was diagnosed, I wanted to know more. (Woman, age 26-35, with relapsing remitting MS)*

We found relatively little evidence that diagnosis with MS affected how people chose to seek information, or the formats in which they preferred to receive information. Their preferences for how they wished to obtain information about MS, and in which formats, were apparently in line with their general preferences about how to obtain information in relation to other aspects of their lives. However, in many cases, knowing more about what kind of MS they have impacts on what people want to know and focuses minds on information relevant to their own diagnosis.

A number of people wanted more specific information on the type of MS with which they had been diagnosed.

*Once I was told it was relapsing remitting different questions came to mind. So the question was, when will it stop? I only wanted to know about relapsing remitting. (Woman, age 26-35, with relapsing remitting MS)*

*I have gone onto the MST website etc and now I understand, but the type of MS and what it meant wasn't explained. Relapsing remitting – the title tells you a lot, but I had to research it myself. (Woman, age 26-35, type of MS uncertain)*

*I just wanted to know about PPMS. (Woman, age 46-55, with primary*

*progressive MS)*

*I was most interested to see that there were different kinds of MS. Mum had had primary progressive MS. I just assumed the same would happen to me and I'd be housebound. When I found out about relapsing remitting I realised it was different. (Woman, age 36-45, with relapsing remitting MS)*

Diagnosis was also sometimes a trigger for wanting more information on possible options for management and treatment.

*I wanted to know what kind of treatment was possible. (Woman, age 26-35, with relapsing remitting MS)*

People also wanted to know more about how their MS might develop.

*Almost a year after diagnosis I wanted to know how and if and when I'd know if it became secondary progressive. I did get the answer: when you start getting new symptoms. (Woman, age 36-45, with relapsing remitting MS)*

### **3.2. Where people newly diagnosed with MS seek and obtain information**

People newly diagnosed with MS obtained their information from a variety of sources, and often from several different sources. These included:

- General internet searches, using search engines such as Google
- Specialist websites e.g. MS Trust and MS Society
- Printed publications (e.g. information leaflets, magazines, newsletters and books; stories from other people with MS)
- Healthcare professionals, e.g. neurologists, physiotherapists, occupational therapists and most of all, MS nurses
- MS Resource centres/therapy centres
- Online forums and chat rooms
- Other people with MS
- Other people, not with MS (including family and friends)

#### Why they choose those sources

On the whole, people newly diagnosed with MS, and their families, choose their sources of information for one of several reasons:

- Recommendations/signposting from healthcare professionals
- Continuation of usual information-seeking behaviour (e.g. customary use of Internet or preference for books)
- Deliberate decisions to seek out either specific formats (e.g. internet or print media) or specific types of content (e.g. medical management or complementary and alternative therapies or diets)

- Preference for personal contact, or otherwise
- Prior knowledge of sources e.g. from work

The reasons for these choices, and for the format in which information is provided, are explored in more detail later on, but a number of people do not mind where their information comes from or how they access it, as long as it is seen to be helpful and reliable.

A few people would have preferred more guidance on sources of information.

*I just type in MS and look anywhere – not a good thing, with hindsight. There is too much and you can really worry yourself. I'd have preferred to be guided on which sites to go on. (Man, age 26-35, with relapsing remitting MS)*

*There was no direction given by the neurologist to any particular sources of information. He may have mentioned MS Society perhaps, I don't remember. I was searching a little bit blind. (Man, age 46-55, with secondary progressive MS)*

And people sometimes had very specific personal reasons for why they went to particular sources of information:

*Although it sounds silly it was the colour as well. I had suspected I had MS for 10 years. I would see people collecting for the MS Society with orange tins and I knew I might have a need of MS services later and I was in denial. Seeing the orange site once I was diagnosed put me off and I preferred the blue. (Woman, age 46-55, with relapsing remitting MS)*

One woman said that she made choices that enabled her to obtain information in spite of cognitive difficulties. So, for example, she was now less able to receive information verbally:

*I was a good listener but I am no longer a good listener. I interrupt as I'll forget what I was going to say otherwise. (Woman, age 46-55, with secondary progressive MS)*

### **3.3. Information needs of families and friends of people with MS**

#### Their role in obtaining information

Family and friends and others close to people with MS are sometimes involved in obtaining information, both for their own use, for other members of the family and for the person with MS. Sometimes, the information needs of family members exceed or emerge more quickly than those of the person with MS. As one man explained:

*I'm not really interested in information, though I might be a bit more now. It was mainly my mum that looked and she panicked even more. (Man, age 26-35, with relapsing remitting MS)*

*I wanted the stuff you can't get. What he'd be like, how it would affect him... .... He was a bit shell shocked and did not want to know anything. I was looking for more information than he was...He still tends to avoid looking at what might happen. He was wary of coming across information he might not want. (Woman, age 36-45, wife of man with MS – type of MS uncertain, possibly remitting relapsing)*

Occasionally, families found 'information' that was not so helpful to the person with MS:

*My mother calls me up and says "darling, they've found a cure" and I say "where did you read that?" and she says "the Daily Mail" and I say "did you read to the end of the article as I guarantee it will say it is in stage 1 or stage 2 trials?" ( Focus group participant, woman, age 25-36, with relapsing remitting MS)*

In some cases, family members had already received information from or sought information for other people in the family who had been diagnosed earlier, or for their own use if they too had MS.

Sometimes, previous experience of MS, either from family or friends, presented a bleak picture.

*Mum also went on a bit of an information bender! ... When I got my diagnosis mum left the room and I could see she had been crying. She thought the worse because of back-in-the-day experiences. (Woman, age 26-35, with relapsing remitting MS)*

#### Their own needs for information

Some of the information needs of those close to people with MS were similar to those of the person with MS – for example, basic information about MS. However, family members also had needs of their own, which sometimes differed in content or emphasis from those of the person with MS. Like people with MS, family members vary as to how much they want to know and how soon after diagnosis they want information. Some want to know very little:

*My partner does not want to know. It's just how he is. He sees me well. He knows I inject once a week, but he just doesn't want to know. (Woman, age 46-55, with relapsing remitting MS)*

Others are too shocked to process information, at least at first:

*To be honest, I was so shell shocked that whatever information I was given, I couldn't take in anyway. (Man, age 36-45, father of woman with relapsing remitting MS)*

Others wanted to know more:

*My partner needed a lot of information. He's been brilliant. He reads a lot about it. He picked it up at the hospital ... He reads it alone and I have brought him stuff home. (Woman, age 36-45, with relapsing remitting MS)*

*I wanted to know what the bottom line was. I tend to deal with things in a black and white way. I was shocked it was such an uncertain thing. (Man, age 46-55, husband of woman with relapsing remitting MS)*

Obviously, all families are different and their information needs and preferences differ too. For example, we heard of one family where older family members wanted the person with MS to immerse in holy waters, in accordance with religious and cultural factors. In that case, the person with MS felt that her family did not understand MS.

We also heard of one instance where a same-sex partner had found it relatively difficult to access information.

#### *Causes of MS*

We heard from both people with MS and from family members about family needs for information about the causes of MS. In particular, family members wanted to understand whether MS was a genetic/familial condition, or whether they had caused it in some way, and whether they were likely to get MS themselves.

*Mum wanted to know if she had done something wrong. I wanted to know if I had done it to myself. (Woman, age 26-35, with relapsing remitting MS)*

*I've also been through "is this something I gave her that hasn't yet happened to me?" And if it does happen to me, who will look after her? (Man, age 36-45, father of woman with relapsing remitting MS)*

#### *Information about MS symptoms*

Some family members wanted information on MS symptoms, including a recognition of the impact on family members.

*You don't get enough information on night time spasms and poor sleep. The effects on carers of fatigue and poor nights is missing (Man, age 56+, husband of woman with primary progressive MS)*

#### *How to support the person with MS*

Some people with MS noted that those close to them needed information

on how to support them, without making too much fuss. As one woman explained:

*I don't always require sympathy. Maybe I should be more understanding about how they feel. So I don't tell others much as I don't know how they'll react and I don't want people watching for every time I stumble. (Woman, age 36-45, with relapsing remitting MS)*

Family members also wanted to know how best they could support the person with MS. Some family members particularly wanted information and support to help them cope with emotional lability (mood changes) and cognitive problems.

*What I needed – and need – is guidelines for coping and dealing with things. I got it, a little, but most of what we've learned, we've learned by trial and error. It's especially difficult coping with her emotional lability. A book will just be full of generalities. It needs to be someone who knows both of us. (Man, age unknown, husband of woman with secondary progressive MS)*

#### *Information on support for families*

One person was particularly aware of her family's need for information on sources of support for themselves:

*When you're diagnosed, everything is centred around the patient. However, one of the things I was concerned about was whether my family were getting the support that they needed in order to help me. It would be useful for family members to be provided with information about support services that are available if they have to become carers etc. (Email, woman age 26-35, with relapsing remitting MS)*

#### *What the future holds*

Family members may want to know how they can cope if the person with MS becomes less able to do things for himself or herself. One man felt that, due to his wife's increasing disability, he was faced with the prospect of engaging in more social activities on his own and he was interested in having information on how others managed this challenge.

### **3.4. Sharing information with others**

People with MS held a wide range of views on whether to discuss their MS with others, such as their wider circle of family and friends and their employers. Access to suitable information was sometimes a factor at time of decision-making about disclosure:

*I'd have liked information on who needs to know. (Woman, age 46-55, with relapsing remitting MS)*

*You have different needs at different times. You don't know if you will want people to know. So information on how to talk to other people and how they can support you and where they can get support - that would all be useful. (Woman, age 36-45, with relapsing remitting MS)*

Some people acknowledged that their reluctance to share information about MS with others was part of their own denial at the newly diagnosed stage:

*There was a lot of denial with others. My parents were elderly etc. And I had a sense of shame, embarrassment. It's a taboo subject. I was embarrassed I couldn't function as I could before. I just wanted to feed information to them in a casual way - like "oh, they say I've got MS, but I don't think I have really". (Woman, age 46-55, with relapsing remitting MS)*

For others, non-disclosure, or limited disclosure, was a more positive decision, bound up with not wishing to be labelled and just wanting to get on with life.

*I don't need to know more than I do. I don't classify myself as someone with MS. It's just part of the person I am and I don't need to explore it further or discuss it with others. It's just part of my life and I don't want to be defined by it. I just get on with it. (Woman, age 26-35, type of MS uncertain)*

A few people had told friends, but had then found their responses difficult to handle. One woman said that she had told friends but then shut them out as they had sent text messages for support, which made her feel worse. Another woman said she did not always want sympathy and so she did not tell others as she did not know how they would react.

People sometimes withheld information from their children, or at least avoided discussion with them, as they wished to shield them from distressing information, and also because genetic issues were very difficult to think about.

Some people with MS had been open and frank with employers, while others had tried to conceal their symptoms and/or diagnosis.

*.. as for work colleagues ... they haven't a clue and they don't need to know. I worry about being labelled and condescended to (Woman, age 26-35, with relapsing remitting MS)*

### Experience of material to assist in sharing information with others

A number of people had obtained information that helped them to share information with others. Several people mentioned an MS Trust publication that had helped them share information with children.

*The book for children worked well. I have an 8 year old son and I did not know what to tell him. But there were flowers all over the place and my mum was always here, and a neighbour came round as she was worried about me. I was worried he'd think I was dying. The booklet really helped him. Now he reads it and uses it as a way to talk to me. (Woman, age 36-45, with relapsing remitting MS)*

One person had used both material designed for younger and older children for her family. She wanted them to have simpler information first and then move on. Like others, she also used material designed for children to explain things simply to adult relatives. Similarly, a family member had used children's material for his own needs:

*Came home and found [husband's name] reading the MS website and he said he was really embarrassed and I said why - "because I'm reading the one for kids. I started with the other and couldn't cope". (Focus group participant, woman, age 26-35, with relapsing remitting MS)*

Written material was also useful to explain MS to people in the wider circle:

*I've told my son's teacher and got him to take leaflets in. He was beginning to say things like "mummy is too busy to wash my PE kit". (Woman, age 36-45, with relapsing remitting MS)*

Material, such as that from MS Trust, also assisted people in explaining the effects of MS, particularly fatigue. A few people had obtained a stock of leaflets so friends and others could have them.

*I did find lots of information and links and I sent it to friends. I wanted them to know, for example, that if my fatigue was bad and I couldn't go out, not to take it personally. And the Shift MS website is very good. (Woman, age 26-35, with relapsing remitting MS)*

Some people used material to help them explain their situation to employers.

*I took leaflets in to HR and my manager. They had to make arrangements for me for fire drills like use the evacuation chair. (Focus group participant, woman, age 36-45, with relapsing remitting MS)*

*Work have been understanding. I took the booklet in to them before they even asked, just to explain it. (Man, age 26-35, with relapsing remitting MS)*

#### Perceived gaps in information to share with or pass on to others

Unfortunately, not everyone who would have liked information to share with others had found suitable material. As one woman recalled:

*It's a dark place, and lonely. And lonely for the family too. And it would have been darker if I didn't know where to look. I was given no information at all. (Woman, age 46-55, with primary progressive MS)*

*I wanted support for my partner as the hospital was not replying to his queries – although I asked them numerous times to give him information. (Man, age 36-45, with relapsing remitting MS)*

One person wanted more information for her grown-up family. More commonly, people with MS had found information, but it had not struck the right note, particularly for sharing with others. In particular, there seemed to be a lack of positive information and information that offered hope.

*My parents assume I'll end up in a wheelchair and think I should move nearer to them. It would be good to give them some positive information about MS. (Woman, age 36-45, with relapsing remitting MS)*

*It would be useful to have some balancing information - to balance the doom and gloom - to give to friends. (Woman, age 36-45, with relapsing remitting MS)*

One woman noted that a lot of information was more suitable for a long-term partner than for someone at the earlier stages of a relationship. For example, information about incontinence may be easier to impart and to hear in the context of a long term relationship than at the outset.

Others had not found suitable information for sharing with employers and colleagues. One man who had found some had found it to be insufficiently practical.

### **3.5. What is important to people about the information they seek?**

We asked what was important to people about the information they sought, and what they particularly looked for or valued in information relating to MS. Most people offered several factors, in a range of permutations. These are listed and then discussed below, while preferences for format are discussed in a later section.

- Accessibility
- Easy to understand
- Reliability
- Trustworthiness
- Relevance and personalisation
- Appropriate tone
- Proactively offered

## Accessibility

Accessibility means different things to different people. For some, it means that information should be available as and when they want it. For others, it means that it should come in formats that are appropriate, for example if people have visual difficulties, cognitive difficulties or physical issues such as postural problems. Comments included:

*Easy to access; categorised in sections for different people (e.g. if just diagnosed). (Woman, age 26-35, daughter of woman with relapsing remitting MS)*

*I like to type it in and get stuff easily. The MS Trust A-Z is really good. (Woman, age 36-45, wife of man with MS – type uncertain, possibly relapsing remitting)*

*Easy to access. The level it is pitched at. There is some information that is aimed at medical professionals and is not at the right level for someone with MS. (Woman, age 26-35, with relapsing remitting MS)*

Several people made the point that accessibility does not require an information provider to personally deliver or impart all the information that a person wants. Signposting sources of material is a way of making information accessible, and has the advantage that newly diagnosed people can control the flow of information to suit their changing needs and preferences.

## Easy to understand

People wanted information that was straightforward, easy to understand and free from unnecessary jargon and medical terminology. That did not mean that they necessarily wanted information to be over-simplified.

*I'm not medical but I am not daft. I did not want it to be too simplistic or written for medical professionals. (Man, age 56+, with primary progressive MS)*

*It is important to keep it in layman's terms, though it is also good to have the science there – science in layman's language. (Woman, age 26-35, with relapsing remitting MS)*

*I have a scientific background so I am not afraid of technical jargon, but I still want it to be simple and free of jargon. (Man, age 36-45, with relapsing remitting MS)*

A few people emphasised that they needed information to be easily understandable in view of their cognitive difficulties. In general, people preferred reasonably concise information without too much dense text.

## Reliability

The difference in meaning between reliability and trustworthiness – both of which were frequently mentioned – was subtle and not always clear, but for the purposes of analysis we have taken ‘reliability’ to apply to the nature of the material and ‘trustworthiness’ to apply to the sources from which information comes. People newly diagnosed with MS referred to impartiality as an aspect of reliability. They also wanted factual information. For example:

*I needed factual information I could use with my health professionals that explained and justified my decisions which were independent of the consultant. (Man, age 36-45, with relapsing remitting MS)*

*Factual information was helpful for instance describing fatigue, double vision, balance and relapse – a wide range of symptoms. I could go back and use it with my consultant and it was useful having someone’s logo on it to prove I was not imagining things. (Man, age 36-45, with relapsing remitting MS)*

*Reliability. Especially after Googling in hospital, which made me wary of reading all the blogs. I wanted to know facts. When I started treatment, I wanted to know all the facts before I heard about personal experiences. (Woman, age 26-35, with relapsing remitting MS)*

Several people were interested in the evidence behind information. One woman wanted to know about trial results, how drugs were tested and what the efficacy rates were, as well as people’s experiences of using drugs. One man wanted similarly rigorous research evidence in relation to diet.

## Trustworthiness

For newly diagnosed people, trust in the sources of information was extremely important. As we have seen, some people had been on what two people called “an information bender” and had been terribly frightened as a result. In the light of such experience, a number of people felt that trusted sources such as the MS Trust and MS Society should be the first ports of call for information. Many people had been steered in those directions by neurologists and other healthcare professionals.

*I wanted proper sites that had trustworthy information –not people talking on blogs. (Woman, age 26-35, with relapsing remitting MS)*

*The neurologist told me about the MS Trust therefore trusted information. There are a lot of things on the internet – for example the use of spider venom so [you] have to be careful. (Woman, age 26-35, with relapsing remitting MS)*

*I wanted to use sources that were bona fide and that I could rely on. I am sceptical of some of what is on the internet. (Man, age 56+, with primary progressive MS)*

Many people had received information, including DVDs, via their healthcare professionals, that originated from drug companies. Although these were often thought to be helpful, they were often viewed with suspicion because of their source, which was seen as biased and focussed on marketing.

### Relevance and personalisation

While general information had its place, many newly diagnosed people particularly wanted information that was relevant to their own situation and personalised according to their own needs and priorities. The fact that MS is such a variable condition made that all the more important.

*I needed it to be personalised to what I needed, the stage I'm at, and relevant to my life. Woman, age 26-35, with relapsing remitting MS)*

*[I needed] information on what was going to happen to ME - unfortunately this is the one thing you can't get, because of the nature of MS. You have to make educated guesses based on the statistics but sometimes that's not very helpful - I don't want to know that fifty percent of people with MS end up in wheelchairs, and fifty percent don't, because how do I know which half I will be in?(Email, woman, age 26-35, with relapsing remitting MS)*

*I am of an Asian background and there is a support group specifically aimed at Asians .... However, I only found out by accident. .... There should also be information made available for youngsters, for example details of social networking sites, where they can go for support and information. Given that the most common age of diagnosis is in the 20s and 30s, I was given very little information about support available for this particular age group, particularly for people (like me) who are still working full-time and leading very full and busy lives. (Email, woman age 26-35, with relapsing remitting MS)*

Information about support, and opportunities to meet people of a similar ethnic background were echoed by others too. So too were comments about needing information that was appropriate to one's age group, both for young people and older people.

*Being a young mother I'd like information on how a mother is supposed to cope. I can't kick a football or push a bike any more. (Woman, age 26-35, with relapsing remitting MS)*

*At the time I wanted to read more about how it might affect people in my age bracket – I'm 33 – and I'm not married and no kids yet. (Woman, age 26-35, with relapsing remitting MS)*

Information for women with MS as they approach menopause was specifically required too.

Several people wanted information about how they could meet people with MS who lived nearby, and it seemed surprisingly difficult to find this information at first.

For some people, personalisation was about information that was tailored to the kind of MS they had and/or the level of disability that they were experiencing.

*It would be good if the information was specific to the type of MS you have – I don't just mean relapsing remitting, but tailored to you and able to help you understand what's going to happen next. You assume you'll be in a wheelchair. (Woman, age 46-55, with relapsing remitting MS)*

Personalisation is also particularly important for people with MS who already have someone in their family with the same condition. Although there is no clear genetic determinant of MS a number of interviewees and focus group participants were closely related to family members who also had MS, and, in some cases, there seemed to be a need for very specific information to clarify the heritability – or otherwise – of MS, including whether the trajectory of the MS would be similar for all affected family members. Also, we found that people who had family members with MS sometimes had specific needs for information, either to build on what they already knew, or to update knowledge which might be seriously outdated.

Commenting that information is better when it is specifically targeted, one woman suggested that the smaller the topic, the more useful it is. For example, specific information on disability living allowance or on treatments was most likely to be relevant to individuals.

One person felt that information services would feel more personalised if it was more easily possible to speak to the same person on successive occasions.

### Appropriate tone

Many comments were made about the tone of information. In particular, people newly diagnosed with MS deplored the “doom and gloom” tone of much of the information that came their way.

*People worry that MS is the end of the world. Information needs to be reassuring. (Woman, age 26-35, with relapsing remitting MS)*

*Everywhere we go, people are worse than she is, so we don't want to be dragged down to where they are. ... We go for normality wherever possible, but information seems to say that everyone's really poorly. (Man, age 56+, husband of woman with primary progressive MS)*

*I don't want to read too much doom and gloom. It helps if it is slightly light hearted; it helps you feel it is not the end of the world. For*

*example, I saw something about a woman with MS wanting to wear her high heels and making jokes about it, and it makes you feel “I feel like that”. (Woman, age 26-35, with relapsing remitting MS)*

One of the more controversial aspects about the tone of information was whether a personal narrative, through people’s personal stories, was helpful. Stories were equally found to be helpful and unhelpful on the grounds that they were either too depressing, or too unrealistically cheerful.

*I like stories about people who triumph over adversity (though not the kind of story about ones who climb Everest!) (Man, age 56+, husband of woman with primary progressive MS)*

*I do like people’s stories. I’ve got several books at the moment. You can’t believe you’re enjoying reading about people having MS, but they are still working, climbing Kilimanjaro! It can be inspiring. (Woman, age 26-35, with relapsing remitting MS)*

For one or two people, illustrations from individual experiences simply did not feel right:

*I find quotes unnecessary – for example “John Doe says this...” – but I’m not John Doe. (Woman, age 26-35, type of MS uncertain)*

### Proactively offered

Many newly diagnosed people felt that a lot of useful information was available and in many instances they had successfully sought it out. However, information was not usually proffered. This made it more effortful for people to get the information they needed, and at times meant that they did not know of information that might have helped them. This is particularly an issue for newly diagnosed people, who may not know what information is potentially available or from which sources.

*You always have to go digging. They should offer to come to see you. (Woman, age 46-55, with secondary progressive MS)*

*The information is out there but finding the right information that is applicable at that time may not be so easy. (Man, age 36-45, with relapsing remitting MS)*

People did not always ask for information, for fear of being a nuisance, or on the assumption that someone would have offered information to them if it was relevant to their needs.

*I felt I was being a nuisance and a bother. I wouldn’t ring unless I was desperate. It would be good if they kept in touch now and then and*

*offered if I wanted to come and see them. (Woman, age 46-55, with relapsing remitting MS)*

*They [MS nurses] seem to think if you don't call them you must be getting on OK. Now and then it would be nice for them to call you to make sure. (Focus group participant, woman age 36-45, with primary progressive MS)*

*I just wanted to be given even a leaflet, a pamphlet. I could have looked for it, but I thought if I was supposed to have it, I'd have been given it. (Woman, age 56+, with relapsing remitting MS)*

A proactive approach would seem to be particularly beneficial in respect of information about support.

*If I was made more aware of how I could get someone to support me, I might. I wouldn't know where to start. (Woman, age 36-45, with relapsing remitting MS)*

However, it is worth noting that a minority of people saw the quest for information as their own responsibility. Indeed, one person felt more in control if she looked for the information she needed:

*I probably wouldn't have wanted it handed on a plate. So much information is available and some you don't want to know about it. It's more in my control if I go looking for it. e.g. I may look up fatigue, but I may not yet want to know about incontinence. (Woman, age 46-55, with relapsing remitting MS)*

### **3.6. Preferences about format of information**

Most people had a preference for the format or formats in which they received information. Many people were comfortable with a number of alternatives, and were as concerned about the content as the format. Some positively liked a range of formats.

*I like having different ways of accessing information. (Woman, age 36-45, with relapsing remitting MS)*

*You need a wide range of options available, all in detail, and you can bypass what you don't want. (Woman, age 26-35, with relapsing remitting MS)*

People often clearly articulated why they liked different formats, either for different purposes or for use at different times.

*I quite like both online and booklets. I tend to look online and then order the booklet to browse through, and I put it in my MS folder. If I am just*

*looking casually online is great. If I want it for reference I prefer it in a folder. (Man, age 56+, with primary progressive MS)*

*I use the internet and printed publications. In the beginning publications are particularly good as you can pick them up and put them down. (Woman, age 36-45, wife of man with MS – type uncertain, possibly remitting relapsing)*

Whatever the format, branding and design may be important factors in guiding people towards information. While many people could not recall where they had obtained their information, some identified both the MS Trust and the MS Society by their respective colours and by “the look” of their material.

A number of formats were mentioned by those who expressed a preference and these are listed here and discussed below:

- Internet searches
- Material downloaded onto different platforms
- Videos, DVDs etc
- Chat rooms/forums
- Social media
- Telephone helplines and information services
- Paper-based resources (publications, leaflets and books)
- Personal contact with health professionals and others

### Internet searches

For very many people, searching online and using the internet had become a natural way to find out information of all kinds, and information on MS was no exception. The internet offered opportunities to search for what was relevant to their current needs and preferences and to sift out what was not relevant. It also enabled people to go at their own speed and to customise the way in which material, appeared on the screen. Internet searches also allowed people privacy as they sought information.

The downside of general internet browsing was that it was not always easy to discern what information was reliable and what was not. It was also difficult for people to avoid seeing information that they did not wish to have, or to be exposed to very gloomy information (although for some, it was also their preferred way of obtaining more hopeful information). Also, the internet is a worldwide medium and search results were not always seen as relevant to a person with MS in the United Kingdom.

*The internet seemed more geared towards me. And it was easier to sift through to find what I was looking for. It was written so it was easier to engage with. Online information seemed friendlier (Woman, age 26-35, with relapsing remitting MS)*

*I always like to do research. It is convenient to use the internet. You don't have to write down what you want to ask. I can do it in my own time and take however long I need. And the internet is just part of my life. (Woman, age 36-45, with relapsing remitting MS)*

*The internet takes you down spooky avenues and you get depressed as hell. (Man, age 56+, husband of woman with primary progressive MS)*

### *Specialist websites*

Some people liked the format that the internet provided, but within that they preferred to look at specialist websites, and particularly those that had some standing amongst MS professionals. The MS Trust and the MS Society were commonly mentioned, and had often been endorsed by the recommendations of health professionals.

### Chat rooms/forums

Chat rooms and online forums elicit strongly opposed opinions. For some, they provide information in a way that is human and reassuring, and can provide support alongside information. For others, they are seen as unhelpful, pessimistic and favoured by people who liked to “moan”.

*You get to talk to people who know what you are talking about. It's good having someone who understands it and is living it themselves. (Man, age 26-35, with relapsing remitting MS)*

*I found online forums helpful, though I like to read them, not to post myself. (Woman, age 26-35, with relapsing remitting MS)*

*The chat room said “I'm leaving my husband as he wets himself”. This was not helpful. (Focus group participant, woman, age 36-45, with relapsing remitting MS)*

*I did subscribe to two MS forums but I did not find them very helpful. The regular contributors tend to be all doom and gloom and I can't be done with this. I'm a cup-half-full sort of guy. (Man, age 56+, with primary progressive MS)*

One woman said that she found some online forums particularly vitriolic about natural management of MS, so she did not feel she could be honest about how she tried to manage her MS.

### Social media

Social media, such as Facebook and Twitter, appealed greatly to some and not at all to others. One woman was extremely positive:

*I use Twitter. It is easy and feels natural, like walking down a fantastic street. (Woman, age 36-45, with relapsing remitting MS)*

Most people had more reservations. Several people followed social media but did not post material themselves. Some were concerned about sharing private information so widely. Others felt that it would bring them into contact with people of a more negative disposition than themselves. It is also possible that there is an age factor at work, but although some older people felt that social media did not come naturally to them, there was little indication that newly diagnosed younger people were generally any more comfortable with social media for the purposes of obtaining or sharing information about MS.

*I am on Facebook, but I never use it. I am wary of sharing personal information. (Woman, age 36-45, with relapsing remitting MS)*

*I wouldn't use Twitter or Facebook for this kind of thing. They're very impersonal and everyone can see it. It's not something we'd want to discuss with everybody. (Woman, age 26-35, daughter of woman with relapsing remitting MS)*

*Not social networking! In the last year I did join a social networking site and it seemed full of fun stuff to start with but it got too heavy so I have deleted it. (Woman, age 46-55, with relapsing remitting MS)*

#### Telephone helplines and information services

Generally, newly diagnosed people and their families preferred not to use the telephone for obtaining information, or if they did, it was a means of obtaining information in another format e.g. printed material. One person said she did not know how to start a telephone conversation and could only do so if she had first prepared herself by reading on the internet. Rather than calling telephone helplines, those who did use the telephone preferred to call someone they knew, such as their MS nurse.

*I haven't used any phone information services or anything like that – that would be my least favourite option. (Woman, age 36-45, with relapsing remitting MS)*

*Helplines – yes, I used them a couple of times at first (I can't remember which) but generally I call my nurse. (Woman, age 18-25, with relapsing remitting MS)*

*When I hear the answer machine I think its not urgent and don't want them to waste time ringing back when they are dealing with more urgent cases. (Focus group participant, woman, age 36-45, with relapsing remitting MS)*

*I don't like getting information by phone as it feels like asking for help. (Woman, age 46-55, with relapsing remitting MS)*

It may be inferred from some comments that a more positive approach to seeking information by telephone may develop after the newly diagnosed phase, when it is easier to talk about having MS and when people may be more aware of what they particularly wish to know.

#### Paper-based resources (publications, leaflets and books)

Printed material was liked and preferred by a number of people for several reasons. First, it was seen as intrinsically more reliable. There was a perception that, by comparison, anything could be published on the internet, but books and leaflets were, somehow, more reputable. Second, people like print for the permanence it offered (whereas online material came and went), and so they could easily refer to it and distribute it to others if they wished. Thirdly, some people found print easier due to visual difficulties, although others preferred computers for exactly the same reason.

*Written information is important as it is easy to forget or get muddled. Also then have a physical document to refer to. (Woman, age 26-35, with relapsing remitting MS)*

*I have no preference for format or source so long as it is there and not going to go away, which is not always the case with websites. In some circumstances, paper is better as you've always got it. (Woman, age 46-55, with relapsing remitting MS)*

*It was important that I could order publications. I have optic neuritis so not easy to read a computer screen. (Woman, age 26-35, with relapsing remitting MS)*

*Printed is best – in bite size chunks. I like finding out where I can get it from the internet, but then get it as printed information. (Woman, age 26-35, with relapsing remitting MS)*

*Books are more reliable – you can't just print a book if it is not true. The internet can be scary or it's just people trying to make a dollar. (Man, age 26-35, with relapsing remitting MS)*

People's preference for print also depended on leaflets etc being well designed and easy to read. Where they had been given leaflets that had been repeatedly photocopied, they did not like them at all.

#### Downloadable onto different platforms (i-pad, Kindle etc)

Only a small number of people mentioned the use of i-pads or Kindles, but those who did were very keen on those formats.

*Kindle is the best thing ever for MS people. You can change the font size and carry it about. (Woman, age 36-45, with relapsing remitting MS)*

*You can sit in bed with your i-pad. You need to get information just when you need it. (Woman, age 46-55, with relapsing remitting MS)*

*I have a Kindle and I have downloaded some information on MS onto that. I can read it at my leisure in private and it doesn't lie around reminding people I have MS. (Woman, age 26-35, with relapsing remitting MS)*

### Videos, DVDs etc

In principle, visual formats, such as videos and DVDs were particularly appreciated by people who did not like to read, or were less able to do so. However, as we have seen, many people had reservations about the DVDs they had seen, particularly if they came from a commercial source.

*I like YouTube. Sometimes when you are reading, you can forget words and lose concentration. So videos are good. You can re-watch them, and there is so much information to take in. (Woman, age 36-45, with relapsing remitting MS)*

### Personal contact with health professionals and others

Many newly diagnosed people preferred to get information face to face from a health professional whom they knew or could get to know. Foremost amongst these were specialist nurses, although other health professionals featured too. GPs were conspicuous by their absence as information providers. This was a considerable problem, since they were often the first port of call, both at diagnosis and when needing particular help and information later on, such as in relation to applying for parking permits for disabled people.

*GPs are useless. Don't tell you anything (Focus group participant, woman, age 36-45, with relapsing remitting MS)*

Also, as we have seen, consultant neurologists apparently varied enormously in the extent to which they imparted or signposted information.

Comments about specialist nurses varied according to the level of service received, and to whether a positive relationship had been forged. On the whole, MS nurses were valued for the mixture of their experience and the personalised service they could offer.

*We need the nurses as the websites only give generic answers not related to self. (Focus group participant, woman, age 36-45, with relapsing remitting MS)*

*If they took the MS nurses away I don't know what I'd do. (Focus group participant, woman, age 36-45, with relapsing remitting MS)*

For some people, contact with a health professional was valued because they were professionally interested and not too emotionally involved – perhaps a pertinent issue for people who are in the early stages of coming to terms with a life-changing condition. However, many people agreed that the health professional had to be proactive and offer to see them. If they did not do so, people newly diagnosed with MS might feel that they were being a nuisance and might think that nurses and others were mainly for people with more extensive problems than their own.

*I don't read books or go on the computer. It would have only gone over worst case scenarios. But I'd go to my MS nurse, she can help me. (Man, age 26-35, with relapsing remitting MS)*

*Time given by professionals is what matters at the beginning. To be able to ask questions and take in the information. (Woman, age 46-55, with relapsing remitting MS)*

*Face to face is best – so long as it's the right face. (Woman, age 46-55, with relapsing remitting MS)*

*It's most important for me to speak to someone as I know I'm getting the right information. (Woman, age 18-25, with relapsing remitting MS)*

*My MS nurse is on email and I can email her, which is fantastic. (Woman, age 26-35, with relapsing remitting MS)*

Contact with other people with MS, particularly in the context of courses for people newly diagnosed with MS were also seen as very good ways of getting both information and support.

### **3.7. Does information for newly diagnosed people affect decisions and lifestyle choices?**

We were interested to know whether people newly diagnosed with MS used information to affect their decisions and how they lived their lives. A substantial proportion felt that information had influenced their decisions in some way, sometimes simply as part of the process of realising that they could take decisions and retain some control over their lives.

*It made me realise that although I have this condition, I can still do different things. Life is not over. (Woman, age 46-55, with relapsing remitting MS)*

*Yes, the information was helpful. It was for reassurance and also so we could make plans. Whether we'd have to make changes to our lifestyle, accommodation etc. (Man, age 46-55, husband of woman with relapsing remitting MS)*

*Yes, it's made us think "let's do it" about having holidays etc while we can. (Woman, age 36-45, wife of man with MS – type uncertain, possibly remitting relapsing)*

Sometimes information had helped people decide not to make radical changes in their lifestyle, or they had decided not to embark on certain therapies because of the information they had seen.

*You see some stuff and think, mmm, I don't think hypnotherapy is going to cure MS! (Woman, age 36-45, wife of man with MS –type uncertain, possibly remitting relapsing)*

Where specific decision-making areas were mentioned, these were most commonly in relation to one or more of the following:

- Work
- Disease management options
- Complementary and alternative therapies
- Nutrition
- Exercise and activity levels
- Psychological wellbeing
- Assistance with daily living

### Work

Advice and information were valuable to people on deciding whether to continue to work and how to achieve a suitable work-life balance, taking into account factors related to MS such as fatigue. This resulted in decisions to reduce the number of hours or to work from home. For a small number of people, information about the demands of work were useful to support changes of role in their current employment.

*I went to a work clinic, focussed on what I could do to make the job easier. As a result, I decided to go part time to get a better work-life balance. I only dropped 5 hours a week but by working a slightly longer day I can do one day less. (Woman, age 26-35, with relapsing remitting MS)*

### Disease management options

Information played a crucial role in helping people make decisions about which, if any, disease management options they chose. Information was as important in ruling options out as in making positive choices.

*All the information was helpful as I wanted to have a full picture – and it helped me decide what [treatments] not to do. (Woman, age 26-35, with relapsing remitting MS)*

Decisions about medical management, and in particular, disease modifying drugs (DMDs), was of great interest to many newly diagnosed people. Some people had acquired information and knowledge prior to their own diagnosis, if other family members had been diagnosed before them, and in some cases they had given thought as to what their own choices might be.

For many people, the decision on which DMDs to take was fraught with difficulty. People were given information by neurologists and MS nurses, often in the form of DVDs. However, advice to accompany the information or to support decision making was often perceived to be absent.

*I did look at a website about treatments, but I wanted my consultant to say “you need this”. I didn’t know what injection I needed and I did not want to be bogged down with that kind of information. (Woman, age 46-55, with relapsing remitting MS)*

*It was “you pick the one you fancy and we’ll go along with it”. I felt like it is at the bank with ISAs when they say they can’t possibly recommend one! (Woman, age 46-55 with relapsing remitting MS)*

*They wouldn’t give me advice on what drugs to have. You have to make up your own mind. I would have liked someone to be more directive. You’re choosing from the unknown. (Woman, age 36-45, with relapsing remitting MS)*

*I did a pros and cons list myself, but for some people it would be helpful to have your choice guided. At the time, you may not be emotionally capable. (Woman, age 36-45, with relapsing remitting MS)*

Some people had made decisions with the help of publications such as the MS Trust’s booklet on disease modifying drugs therapy. They had found this to be extremely helpful, as was the Department of Health funded MS Decisions website ([www.msdecisions.org.uk](http://www.msdecisions.org.uk)).

One woman wished she had had more choice about whom to consult with. This may be a particular issue for people who work in the NHS and may be reluctant to discuss their health issues with work colleagues.

### Complementary and alternative therapies

There is some overlap between this section and the next as people who were interested in complementary and alternative therapies were often also interested in nutrition. Information on holistic approaches to managing

MS that went beyond a medical model was not always available as people wished, so it is not easy to understand how far information they actually received affected their decisions and lifestyle. Rather, it appears to be the case that people began with a desire to explore options including complementary therapies and then started looking for information to support that approach. It was not unusual for people to have had an interest in such approaches well before they experienced MS symptoms.

*Initially I wanted to understand what was happening, then how I could tackle it. And what treatment to have? And what life changes I can follow. I want a holistic approach, not just a medical approach. (Man, age 36-45, with relapsing remitting MS)*

*I always take my own health into my own hands. .... I like to be in control. I wanted to know what was likely to happen.... I was looking for natural ways to treat it, ... I had treated my bowel problems by modifying my diet and I had learned about raw food. So that's what I would search for. I wouldn't look at drugs and information from drug companies. I like to find a natural way. (Woman, age 36-45, with relapsing remitting MS)*

*I was looking for - not drugs as I knew if there was anything the neurologist would have offered it - but I'd heard of bee-sting treatment and I'd heard of a chiropractor who was claiming he'd cured people and I'd also heard about the oxygen treatment. And a gluten free diet. These were the sort of things. (Man, age 46-55, with secondary progressive MS)*

*I'm starting to learn about mindfulness and meditation and hoping to do more exercise. There are things I was interested in more than 10 years ago, but I had put them on hold. (Man, age 36-45, with relapsing remitting MS)*

## Nutrition

A great number of people wanted information on nutrition, including vitamin D and other vitamins, herbal supplements and special diets for people with MS. A few people had tried fairly extreme diets and had found that they were too hard to follow and felt that the results did not justify the difficulties of following the diet. Others followed diets recommended by, for example, Professor Jelinek and Dr Swank, as a result of information that they had usually found from their own researches. Some people had taken a different approach, modifying their diet (and other aspects of their lifestyle) in the light of information in order to live a generally healthier life.

*My diet is vegan. It has arrested the decline. You do get used to it. It's not easy but it is better than the alternative. (Man, age 46-55, with secondary progressive MS)*

*Information on diet and exercise made me feel normal, not like [own name], the one with MS”, as it was just common sense and what we should do anyway. (Woman, age 26-35, with relapsing remitting MS)*

*I did change my diet, but it didn’t make a difference so I thought why am I putting myself through this? (Woman, age 56+, with secondary progressive MS)*

The motivations for following strict diets appeared complex. At a most basic level, people spoke about hoping that these approaches would improve their MS symptoms or delay relapses. Beyond that, people also spoke of wishing to be in control, and managing their nutrition was a way of doing so. Interestingly, sometimes people made changes to their diet in the light of information they had read about even if they were not convinced of any direct benefit, because taking control was itself a positive action.

*I wanted to know about herbal supplements as that makes me feel in control (Woman, age 26-35, with relapsing remitting MS)*

*I am more aware of what I am eating. I take supplements like cod liver oil and evening primrose oil. I know it is something good and I am doing something active even if it doesn’t work. It makes a positive change. (Woman, age 26-35, with relapsing remitting MS)*

### Exercise and activity levels

People wanted, but did not always receive information on how active they should be and how to exercise. But when they did get such information, or work it out for themselves, it sometimes had a direct effect on their lifestyle.

*And the OT said – the main thing that’s helpful – to have a rest twice a day. If I’d just read that online, maybe I wouldn’t have taken it on board. (Woman, age 36-45, with relapsing remitting MS)*

*I hoped I could fight it. I had always been very active and spent a lot of time in the gym. But I was losing fitness incredibly quickly, but I realised if I exercised a lot more I could break through it. I did a lot of hill walking etc. But when it first started I couldn’t even walk across a room. I just worked it out for myself. (Woman, age 56+, with secondary progressive MS)*

### Psychological wellbeing

Information and advice on psychological wellbeing was seldom available at the right time or in the right way to enable people newly diagnosed with MS to make decisions or change their lifestyle.

*My GP asked me which antidepressant I wanted. I had no idea  
(Woman, age 46-55, with secondary progressive MS)*

*Clinical and factual information was all there, but not the emotional  
stuff. That was not really touched upon. (Woman, age 26-35, with  
relapsing remitting MS)*

Most of the people who had attended short courses and information days for people newly diagnosed with MS had found them to be helpful sources of information and support. However, for a minority, such events were not helpful, or not acceptable to them at the stage they were at:

*It was the most depressing day I've ever been on. I wanted to do it myself and have time to take it in. And it was like "competitive MS", so I have since stayed away from support groups. I wanted to do it privately, not with people I did not know. There was/is still a huge amount of denial. I refuse to categorise myself. It sounds terrible to say it, but people think having MS makes them special. Some one even said they saw it as a gift! I don't see it as a gift or as a blessing, but as a burden to be overcome. (Woman, age 26-35, with relapsing remitting MS)*

#### Assistance with daily living

Little material came to light about the role of information in helping people to make decisions or change their lifestyle in relation to practicalities and assistance with daily living. Indeed, a small number of people specifically noted the lack of such information.

Two people mentioned that information on functional electrical stimulation (FES) machines had been helpful.

### **3.8. The role of formal support in seeking and using information**

#### The need for support

A consistent theme from the fieldwork for this research was that information alone is not always sufficient. Particularly when people are newly diagnosed they may need support in understanding information and in developing a state of mind in which they can assimilate information. For some people support from family and friends is adequate, but as we have seen that does not suit everyone.

Support from others with MS suits some and not others, but in any case, newly diagnosed people may not be in touch with suitable sources of peer support. So, for some people, formal support from health professionals or MS charities and other organisations may be necessary. Often, MS nurses, and sometimes other health professionals, can provide this support and assist people to make use of information, but that does not always happen.

*The MS nurse is apparently very good, but she's just one person, and I wasn't pointed towards any other service that could help me. In that time, I really needed to talk to someone about how to come to terms with it, and to be told you can do this and that. I didn't want to go to a group or use online forums where people just sit and moan. (Woman, age 36-45, with relapsing remitting MS)*

*You need direction where to find things and support to use the information to make decisions (Woman, age 36-45, with relapsing remitting MS)*

*No-one knows MS and no-one knows how to help you. The medical profession only offer you medical services. ... and there is a lack of emotional support. (Woman, age 36-45, with relapsing remitting MS)*

### **3.9. Experience of using MS Trust's Information Service**

We asked people if they had experience of using the MS Trust's Information Service, and if so, what they thought about it. It was noteworthy that people often did not recall where they had obtained their information, and while some were certain that they had used the MS Trust, others had used the MS Trust and the MS Society and were not completely sure what information had come from which organisation, or how they rated their respective information.

*I did send off for a foreign language one for my mother-in-law (Gujarati) but I can't remember if it was MS Trust or MS Society. (Woman, age 26-35, with relapsing remitting MS)*

However, those with a clear recall had usually been extremely satisfied with the MS Trust, and quite a few preferred MS Trust information to that from other sources e.g. the MS Society.

*I requested booklets and looked at the website. It was my first port of call and was helpful. The search facility is good. (Man, age 56+, with primary progressive MS)*

*I prefer MST to the MS Society – the MS Society information is very stark. (Woman, age 26-35, with relapsing remitting MS)*

*MST information is easier to read, with more colour. It makes you feel better and doesn't feel so alarming. (Woman, age 26-35, with relapsing remitting MS)*

*Have been very impressed. The important thing is that the information is free and available on line and by post. When first looked for information if I had had to get up and get a credit card to look at information or order it I wouldn't have bothered. (Woman, age 46-55, with relapsing remitting MS)*

People particularly liked the MS Trust's Information Service because:

- It enabled them to find what they wanted
- It struck an appropriate tone and gave people hope
- It did not promote miracle cures and give false hope
- It was easy to search and navigate
- It included material that was relevant to people who were newly diagnosed
- It was free of charge
- Open Door was very interesting and easy to read

### **3.10. What could be done to improve information for people newly diagnosed with MS?**

We explored what people newly diagnosed with MS and those close to them felt could be done to improve information for people with MS. We have grouped their responses into two broad categories:

- Gaps in information for people newly diagnosed with MS
- How information could be better provided

#### Gaps in information for people newly diagnosed with MS

People pointed out several areas where there seemed to be gaps in information provided, or where information had been hard to find.

##### *Information on MS symptoms*

Although most people had found what they needed about symptoms and symptom management, some had not.

*The information problems I've had are about symptoms like itching or constipation, or tips on walking. (Man, age 46-55, with secondary progressive MS)*

The husband of a woman with MS also noted that if a person with MS was having medical procedures performed for other health conditions, it was not easy to find out if those procedures had an impact on the MS.

##### *Better and more timely information on disease modifying drugs*

Most people had been given information about disease modifying drugs, but, as we have seen, it was not always offered in a way that they found most helpful. Also, some had not received it early on, and some were critical of the quality of the information.

*What I wasn't told at my diagnosis was that there were DMDs available so I wasn't aware that there was medication that I could be offered. It was a huge relief when I was told that I was eligible for treatment.*

*(Email, woman, age 26-35, with relapsing remitting MS)*

*I wanted to assess the facts and evidence for myself to support informed decisions rather than being told “it did not matter either way if I took them or not” and “I would not last long on treatments as the side effects were so bad or the injections were so horrible”. (Email, woman, age 36-45, with relapsing remitting MS)*

*More information on complementary and alternative therapies and on nutrition*  
As we have seen, these are topics on which a number of people wanted information, and quite a few of them felt that there were gaps in such information or difficulty in accessing it.

*The MS organisations should give information on things that they don't think are evidence based, particularly if that's because the evidence has not accrued yet. Also, when you think about alternative therapies, I haven't found any that work, but they do for some people. And there's no evidence that it doesn't help. And even if it's a placebo it helps some people so I think people should be made aware. (Man, age 46-55, with secondary progressive MS)*

*I wish there was more information on herbal medicines and more support from nurses and neurologists on supplements. It would be good to have guidance on where to get the information – just to open up the doors, as that one was closed to me by the doctor and the nurse. (Woman, age 26-35, with relapsing remitting MS)*

#### *New approaches to treating MS*

One person felt that it was hard for people to find out about the latest development, particularly if these were controversial or unproven. Information on chronic cerebro spinal venous insufficiency (CCSVI) was a case in point.

*I'm quite interested in that. You have to go to each particular treatment centre to see their results. That's been a bit of a struggle. It would be nice if one of the MS organisations had coordinated a list of treatment centres, and even just feedback from patients who have been to those treatment centres and how they got on so you don't have to go trawling through the forums. (Man, age 46-55, with secondary progressive MS)*

#### *Access to information about counselling and support and ways of promoting psychological and emotional wellbeing*

Several people wanted more information on sources of counselling and other psychological support, particularly that which was available in their local area.

*It is not just about the medication and treatment options, but also the psychological impact it has on you at diagnosis. Signposting people to this type of support and how to access it and how it can help would be*

*one of the most useful things and can have a huge impact on how well you manage your condition. (Email, woman, age 36-45, with relapsing remitting MS)*

### *Employment*

One person told us that it was not easy to find information about entering employment after being a student. Information about work seemed to focus more on those who were already in employment at the time of diagnosis.

### *How to get involved with research*

A few people wanted more information in how they could become more involved with research into MS (clinical and other). Unsolicited comments from participants in this research showed that a number of people felt very positively about taking part in projects such as this one; they liked to help others and to feel that they were contributing.

*I would like to add that taking part in MS surveys of any kind help me feel better and of some use as life for me has altered considerably and I feel more like a spare part and on very down days “surplus to requirements” - but still , life goes on and I have hope and can laugh, especially if I fall over and land somewhere silly. (Email, woman, age 46-55, with primary progressive MS)*

### *Information about sport and leisure opportunities*

A small number of people wanted information about opportunities for people with MS to play sport, particularly competitive sport. Others wanted much more wide-ranging information about leisure opportunities:

*It would be good to tag on information about MS Centres and getting to see someone to do your nails and home visits for hair and nails. And what bridge club and swimming club you could get to. .... And information about holidays. (Woman, age 46-55, with secondary progressive MS)*

### *Information about transport*

One person was still trying to find out about transport. She used hospital transport when necessary, but found it hard to find taxis that took a wheelchair. She felt that better information on transport would increase her independence. One man felt that he had acquired information about transport accidentally and it had not been forthcoming.

### *Information about rights and benefits*

People newly diagnosed with MS reported a lack of information on financial benefits and other services, such as how to get funding for adaptations at home and on parking entitlements. Information about other legal and rights issues and on insurance was not always easily available either.

*It would be good to have information on benefits. I was told MS wasn't a disability, it was a critical illness. But I work full time and I think I might need information on benefits if I progress even further. (Man, age 26-35, with relapsing remitting MS)*

*We struggled to get information on benefits, at least at first. Now the MS nurse has told us about someone at the CAB who specialises in benefits for people with MS – that's fantastic. (Woman, age 36-45, wife of man with MS –type uncertain, possibly remitting relapsing)*  
*There is nothing specific for people on where to go and what their rights are – for instance power of attorney and my will needed to be sorted. (Man, age 36-45, with relapsing remitting MS)*

*It was only when the OT came round and had a look at the house she said I could have a wet room. ( Focus group participant, woman, age 36-45, with primary progressive MS)*

### How information could be better provided

In addition to addressing the gaps outlined above, we heard a number of suggestions about how information for people newly diagnosed with MS could be better provided. First and foremost was a reminder that people differ in many ways so information providers must be sensitive and aware of difference.

*General awareness and it's different for everybody and it is an invisible disease. (Focus group participant, woman, age 26-35, with relapsing remitting MS)*

Second, the issue of tone was important with the main comment being that there was a need for more positive information for newly diagnosed people.

*I OD'd on information, both good and rubbish. I assumed I'd be in a wheelchair by now. I'd just look for all the symptoms. I wish there was more positive information for a newly diagnosed person. (Woman, age 26-35, with relapsing remitting MS)*

Third, people suggested more signposting to suitable information, and more personal support in the early stages to help people find and utilise information. Unfortunately, we heard occasional accounts where even the basics of specialist care and support had been lacking, with appalling consequences for access to information:

*Every person must be supported and allocated immediately to an MS consultant and MS nurse. Going privately, I slipped through the net and we need to stop that happening to others. I've started an e-petition<sup>1</sup>.*

1 See: <http://epetitions.direct.gov.uk/petitions/9918>

*(Woman, age 56+, with relapsing remitting MS)*

*The consultant is a central cog. If he'd said do this or go there I would have found it quicker. I found what I wanted, but not as quickly as I would have. (Woman, age 26-35, with relapsing remitting MS)*

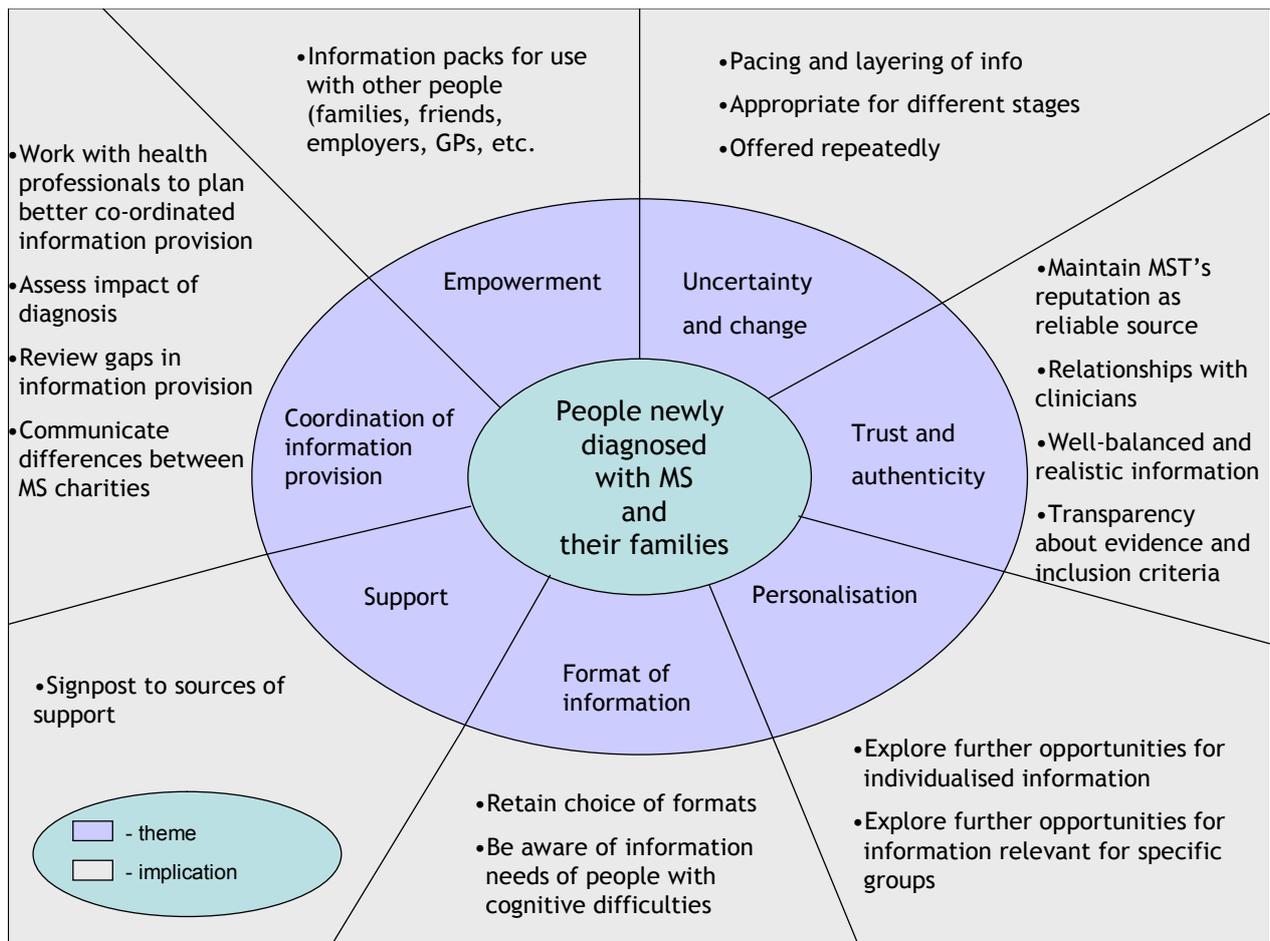
Fourth, although personalised information was very important to people, there was still a need for basic information packs, and these need to be provided in a more consistent manner.

*There could be more cohesion via an information pack for newly diagnosed, with local information. If you join a bank, the first thing they give you is an information pack, relevant for your area. You still have the choice of what you want to access. (Woman, age 46-55, with relapsing remitting MS)*

*I think what would be good -you are in the system somewhere as you are getting a diagnosis – you get an information pack with a checklist and a covering testimonial letter from someone who has MS. (Focus group participant, man age 36-45, with primary relapsing MS)*

At one of the focus groups it was suggested that an information pack for GPs might better enable them to provide and signpost useful material to people with MS and their families.

Finally, several people made suggestions about the need for a more integrated approach to information for newly diagnosed people. This might include the need to educate and involve GPs and the need for the NHS to work more closely with MS charities.



Above: the high level themes that emerged from the research findings and the possible implications for the MS Trust (see following pages).

## 4. Discussion Of Findings

In this section, we consider some high-level themes from the findings and we suggest some implications of these themes for The Multiple Sclerosis Trust. In some instances, there are insufficient data to reach firm and final conclusions but the data that are available suggest areas where further developments and new ways of working may be indicated and/or areas where further research may be indicated.

### **Theme One – The patient journey: uncertainty and change**

People with long-term conditions are often described as being on a journey. For people with MS, that journey is sometimes quite uncertain as it is not possible to predict, with accuracy, how their MS might affect them, or the rate at which symptoms might develop or change.

The patient journey can be very lengthy, beginning even before formal diagnosis, as the possibility of MS may be suggested or presumed before a formal diagnosis is made.

The information needs and preferences of people newly diagnosed with MS and those close to them continue to develop and change over time, and not necessarily in a linear way. The experience of coming to terms with a diagnosis varies from person to person, and as a consequence, people can feel as though they are newly diagnosed for some time after receiving a diagnosis.

People reported fluctuations in their appetite for information, and different kinds of information were important at different times.

#### Implications of Theme One

- As the patient journey is so variable and not always predictable, people with MS and their families may require quite different types of information at different stages, and may wish to have information in more or less depth at various times. Information providers need to focus on how to provide information that can be used in stages and at a pace that is appropriate to meet continually changing needs and preferences.
- Even when information has been provided and assimilated at an early stage, further information may be needed – or need to be offered again – at later stages.
- For most people, information provision is best seen as a process, not as a single event.

## **Theme Two – Trust and Authenticity**

In a context where a huge amount of information of variable quality is available from multiple sources, people with MS and their families want to know that the information they seek and receive is from a trusted source and is reliable and authentic. MST is seen as a trusted source of high quality information.

MST's image of reliability and trustworthiness is reinforced by the ability to be realistic, while still offering hope. Many newly diagnosed people were overwhelmed by what they termed "doom and gloom", particularly from unmoderated sources.

Although the reliability of information is seen as highly important, there is a range of views on whether people should also be offered information on treatments and ways of dealing with MS where the evidence base is uncertain, under-developed, absent or particularly controversial.

### Implications of Theme Two

- The maintenance of MST's reputation as a provider of reliable and trustworthy information should remain a continuing priority.
- It will be helpful to continue to maintain and develop relationships with clinicians and with other information providers so that MST is always seen as one of the most important places to go for information for newly diagnosed people.
- Information about MS for newly diagnosed people should be well balanced, maintaining honesty and realism about how MS can develop, while giving clear and positive information about living well with MS.
- The findings of this project suggest a considerable appetite for information about approaches to MS on which there is not a substantial evidence base, or on approaches which a medical model would not encourage or support. That is not to suggest that there should be an indiscriminate approach to providing information, but rather that information providers should be transparent about their criteria for inclusion so that people who wish to seek other kinds of information know where they stand. More work should be done to explore whether and to what extent MST should provide information on topics where there is not a well developed evidence base.

## **Theme Three - Personalisation**

Personalisation of information is important. Generic information has its place, but information tailored towards individual needs, is also much wanted.

### Implications of Theme Three

- There is scope to further explore how personalisation can be achieved. Information more specifically geared towards young people, women during menopause, families where several people have MS, people living in a specific area and people entering employment may be examples where more personalised information can be made more available.
- Modern technology offers many possibilities for personalising information according to specific requests, demographic data (age, gender, ethnicity etc), type of MS and many other variables.

## **Theme Four – Format of information**

Many people were happy to receive information in a variety of formats, but within that there were often marked preferences. Many people see the internet as their natural source for information, but printed information, and information imparted by a known and trusted person remain important to many.

### Implications of Theme Four

- Those providing information to people newly diagnosed with MS should retain a wide element of choice on how information is provided (i.e. alternative formats).
- Cognitive difficulties may lead to preferences for particular formats, and these may differ for particular individuals.

## **Theme Five - Support**

The findings from this project indicate that for many people information is not their only concern, or even their main one. Support is needed by some people in order for them to be able to make use of information. This is particularly important for people who are newly diagnosed and their families.

### Implications of Theme Five

- While information providers and national MS organisations may or may not offer ongoing support, signposting to sources of support may be very necessary.

## **Theme Six – coordination of information provision**

Both healthcare providers and professionals and voluntary organisations have a major role to play in providing information to people who are newly diagnosed with MS and their families. They can and should also signpost people towards other sources of information that may be useful.

The findings of this project suggest that the availability of information from a variety of sources, and signposting from various sources, are positive features, given the wide range of needs and preferences that people have.

However, we found considerable variation in people's experience of a coordinated approach to information provision. Some people received a great deal of information, and some very little. Occasionally, people received their diagnosis without being helped towards appropriately useful or timely sources of information.

While most areas of information needs were met, at least in part, information about financial benefits and local services was not always provided comprehensively.

There is a lack of clarity amongst newly diagnosed people about the respective roles and remits of the major MS charities. People are not always certain about where they have obtained their information.

### Implications of Theme Six

- There is a need for a greater degree of coordination, in particular so that healthcare organisations are more aware of what voluntary organisations / charitable bodies can offer. This is not a new challenge, but further work with healthcare professionals continues to be needed in order to plan and deliver better coordinated information to newly diagnosed people.
- The experience of diagnosis seems to have a lasting influence on how people find and assimilate information, and is therefore of the utmost importance. From a patient's point of view, information is not in a discrete box, apart from diagnosis, and well-coordinated information provision cannot be separated from the process of diagnosis. A more seamless process of imparting and signposting information may be necessary for many people from the point of diagnosis and, for some, quite possibly before a settled diagnosis is reached.
- All those involved in the provision of information to people newly diagnosed with MS should systematically review areas where there may be significant gaps in information provision. Some of these can be addressed at a national level (e.g. information about benefits) while others, such as information on local services and sources of support, may need to be offered by people with up to date local knowledge.
- For some people with MS, the differentiation between the major MS

charities is unclear and what a person with MS could expect to obtain from each of them could be better communicated.

## **Theme Seven - Empowerment**

Many people newly diagnosed with MS are extremely motivated to look after themselves and care for their own health and in many cases to take an active role in obtaining information to meet their own needs.

### Implications of Theme Seven

- There is scope to further consider how MS organisations can further empower people who are newly diagnosed with MS, and what the role of information is in empowering self-care and self-directed information seeking.
- The development of information packs for people newly diagnosed with MS, with opportunities for personalisation, and incremental information as needs change would seem to be a high priority.
- People with MS may welcome specific information to share with employers, family members, friends, GPs and other health professionals.

## Appendix 1 - methodology

### Recruitment and selection

The issue of how to recruit volunteers to take part in the project in a short space of time was the subject of considerable thought and discussion with MST. There was no way of knowing in advance how many people would come forward. The main means of publicising the call for participants were an article in Open Door and information on the MST website. These approaches generated a very large response (approximately 180 people), mostly from people who had read Open Door. Due to an initial large response, the publicity on the MST website was removed before the closing date.

A further cohort of people came forward later to volunteer for specific focus groups, as a result of a range of recruitment strategies (see below).

While the scope and duration of this study did not permit a representative sample to be selected, we were mindful of the need to include men and women of all ages, who had been diagnosed for different lengths of time and with different types of MS, and from a range of ethnic backgrounds locations in the UK.

We acknowledged expressions of interest and informed people of the timetable for selection and the reasons for making a selection. We then either contacted people to ask them for their consent to take part, or we invited them to submit emailed information about their information needs, preferences and experiences of seeking and obtaining information. Those who were invited to submit information by email were asked three questions:

*When you were newly diagnosed:*

- 1. What information did you most want?*
- 2. Was there any information that you wanted that you could not easily get?*

*And:*

- 3. What could be done to improve information for people newly diagnosed with MS?*

### Telephone interviews

We were contracted to carry out twenty four telephone interviews, mostly with people newly diagnosed with MS, but some with family members. In fact, we were able to carry out thirty four telephone interviews, of which twenty six were with people newly diagnosed with MS and eight with family members. This over-performance resulted from our concern to ensure that we achieved at least the minimum number of interviews, allowing for an expected proportion of interviewees who might not actually be available,

having agreed to take part. In fact, all were available. Another reason for over-performance was a late flurry of interest from family members, mainly as a result of people with MS encouraging their participation.

Telephone interviews varied in length, from twenty minutes to an hour, with the majority taking thirty to forty minutes. Full contemporaneous notes were taken.

The interview schedule for telephone interviews is reproduced in Appendices 4 and 5.

### In-depth interviews

We were contracted to carry out 5 face-to-face, in-depth interviews. A sixth person (the partner of one of the interviewees) was present for a few minutes of the interview, and also made his own comments (with the interviewee's knowledge) while she left the room for a break. Separate consent was obtained for each of them, but in view of the brevity of his contribution, he has not been included in our statistics.

Face-to-face interviews lasted approximately one hour. The venue was negotiated with the interviewees. Two took place at workplaces, two in the interviewee's home and one in a hotel.

Interviews were digitally recorded and contemporaneous notes were taken.

The interview schedule for face to face interviews is reproduced in Appendix 6.

### Focus groups

We were contracted to carry out 4 focus groups, each consisting of between 6 and 8 people. Although resource restraints meant that we were unable to hold focus groups in each country of the UK, we hoped to achieve some geographical spread.

Initially we hoped to recruit via groups that already met, such as a men's carers' support group and an African Caribbean support group. However many of their members had been diagnosed for longer than 5 years.

We also looked for clusters in the area of residence of respondents to our request for participants. However respondents came from a wide range of geographical areas and could not be easily clustered. However two respondents, one in Bournemouth and one in Sheffield took on the task of bringing together newly diagnosed people to form a focus group.

The Sheffield focus group was attended by people who had met on a newly diagnosed course. Although 6 people were recruited only four were able to attend – 3 people with MS and the partner of one of them.

In Bournemouth the respondent was on the committee of the MS Society and together with a fellow committee member was able to recruit 8 people newly diagnosed with MS, including themselves. In addition another respondent who lived in Dorset was able to attend the group.

It was decided, after discussions with the MS Trust, that a focus group should be held in Edinburgh. The focus group date and time were advertised twice on the MS Trust website and the Edinburgh MS Therapy Centre forwarded the advert on the event to its' members. In addition the MS nurse running an MS support group at the Haven centre, East Lothian also tried to recruit people for the focus group. Although 6 people initially stated their interest in attending, on the day only 2 participants (a person with MS and her partner) attended.

The final focus group came about through a neurological support organisation, the Integrated Neurological Service based in West London. Through them, Chairs and members of local MS Society branches stated their interest in attending a focus group. The MS Society Hounslow agreed to host the focus group and 5 people with MS participated.

Across all 4 focus groups there was a range of types of MS, gender, age and ethnicity. Two participants were partners of people with MS.

### **How the material was analysed**

We had a great deal of material from a variety of sources and the challenge was how to analyse it in a consistent manner. Our approach to this was based on the Framework Method. This method was initially developed by (Social and Community Planning Research (SCPR), (Ritchie J, and Spencer L 1994). Framework is a generic method, providing a versatile means for qualitative analysis, rather than being a highly specific technique. It provides a structure to which the researcher can apply his/her own data. It can therefore be applied to a wide variety of qualitative methods of data collection with differing aims and objectives.

Interviewers often develop hunches about themes while they are conducting and noting interviews. The benefit of a method such as Framework is that it allows the mass of data and hunches from the notes and recordings to be organised in a structured way. Essentially, Framework involves 5 key stages:

1. Familiarisation
2. Identifying a thematic framework
3. Indexing
4. Charting
5. Mapping and interpretation.

## **Limitations of the methodology**

Each section of the fieldwork generated similar themes, so we have a good level of confidence that the themes we had identified were indeed the ones that mattered most to people newly diagnosed with MS and their families. In addition, we found that we reached saturation in the interviews before they were all completed (i.e. the later interviews confirmed and reinforced the themes that had been identified in the earlier interviews).

However, we note that small scale qualitative studies are always subject to limitations, and although we achieved a good spread of interviewees, we did not seek to achieve a representative sample of the MS population. In particular, more young people in the 18-25 age bracket might have offered further insights specific to that age group. Also, although there was some ethnic diversity amongst interviewees, greater diversity may well have brought out further points. Finally, although we conducted interviews with people from all 4 UK countries, only one was from Northern Ireland (this was the only person from Northern Ireland who volunteered to take part).

A more serious limitation relates to the fact that many people who volunteered to take part did so as a result of seeing information in Open Door, and it can be assumed that they were already aware, to some extent, of the MS Trust. However, some of the focus groups recruited in other ways, although they too were in touch with some organisation or group of people with MS. We can therefore infer little about the needs and preferences of newly diagnosed people who are not in touch with an organisation related to MS, except in so far as people recalled a time when they were unconnected with such organisations, particularly in the period soon after diagnosis.

## Appendix 2 - ethical framework

The Steering Group and those involved in the management of the project agreed that the scope of the project, its short timescale and the methods of recruitment of volunteers (not using NHS or other healthcare lists) did not require ethical approval from a local research ethics committee via the National Research Ethics Service. However, the researchers undertook to conduct the project according to clear ethical standards. These included:

- A commitment to providing clear information as the basis for informed consent
- Assurances about confidentiality
- Assurances about data protection
- Sensitivity to the wellbeing of participants
- Clarity about risks and benefits of taking part
- Offer of payment of reasonable expenses to those travelling to focus groups
- Clarity about who is funding the project
- Clarity on what will happen to the findings
- Information on how to obtain further information and make a complaint.
- Clarity about the composition of the steering group and its role in ensuring high ethical standards

The steering group oversaw compliance with the ethical standards for this project.

## **Appendix 3 - role and membership of the steering group**

### **About the steering group**

The group met on three occasions, on 27 January 2012, 28 March 2012 and 11 June 2012. It comprised the following people:

#### Academics and Health Professionals

Steven Bloch, Lecturer, Department of Language & Communication,  
University  
College London

Jenny Freeman, Associate Professor in Physiotherapy, School of Health  
Professions, Plymouth University

Richard Warner, MS Nurse Consultant, Gloucestershire Royal Hospital,  
Gloucester

#### Representing the MS community

Graham Bashford, West Sussex  
Helen Newbury, Devon  
Catherine Strange, Hertfordshire  
David Yeandle, Hampshire

#### MS Trust

Amy Bowen, Director of Research Development  
Jane Havercroft, Information Officer

### **Terms of reference**

The following terms of reference were set out for the steering group:

- Overall, the role of the Steering Group is advisory and a critical friend to the project
- Decision making rests with the MS Trust

Key roles:

- Providing perspectives
- Identifying and advising on ethical considerations
- Reviewing documentation and making suggestions/alterations/improvements
- Identifying risks, gaps and ideas for mitigation
- Confirming satisfactory progress
- Problem solving
- Suggesting dissemination routes

## Appendix 4 - telephone interview schedule – people with ms

Confirmation of name, type of MS and when diagnosed. Check consent form signed

Assurance information is confidential and individual comments only shared anonymously

1. When you were newly diagnosed what kinds of information did you want?  
(Prompt: medical information, practical support such as managing job, how to tell other people)

2. Did you actually get the information you wanted?  
(Prompt: was there a difference between what you wanted , what you were offered and what you found out in any other way)?

3. Where did you go to get this information?

4. Why did you choose to get this information from there?  
(Prompt: trusted place, ease of access)

5. What was most important to you about the information you sought?  
(Prompt: where it came from, ease of access, reliability, clarity, tone, quantity)

6. When you were newly diagnosed with MS, did you have any preferences for the format or source of your information (prompts about printed publications/leaflets, online versions of publications/leaflets, website, phone, social networking, MST personal inquiry service etc)

7. Was the information you found helpful and what did you want the information to help you with? ( prompt – understand more about MS, make some decision about your treatment, to get a ‘second opinion’ on what you had been told, to give you reassurance?)

8. Did any information you received affect your decisions or lifestyle in any way? If so, how?

9. What information could you not find that would have been helpful?

10. Did you discuss your needs and the information you received with others? If so who?

11. Were you able to get information that was relevant for your family/friends/ children/employer?

12. Once you knew the kind of MS you had did you need other kinds of information delivered in a different way? If so what?

13. Have you used the MS Trust’s Information Service – did it meet your needs?

14. What could be done to improve information for people newly diagnosed with MS (Prompts: access to information, format, content)

## **Appendix 5 - telephone interview schedule – family members of people with ms**

Confirmation of name, type of MS and when diagnosed

Check consent form signed

Assurance information is confidential and individual comments only shared anonymously

1. When your relative was newly diagnosed what kinds of information did you want?

(Prompt: medical information, practical support such as managing job, how to tell other people)

2. Did you actually get the information you wanted?

(Prompt: was there a difference between what you wanted , what you were offered and what you found out in any other way)?

3. Where did you go to get this information?

4. Why did you choose to get this information from there?

(Prompt: trusted place, ease of access)

5. What was most important to you about the information you sought?

(Prompt: where it came from, ease of access, reliability, clarity, tone, quantity)

6. When your relative was newly diagnosed with MS, did you have any preferences for the format or source of your information (prompts about printed publications/leaflets, online versions of publications/leaflets, website, phone, social networking, MST personal inquiry service etc)

7. Was the information you found helpful and what did you want the information to help you with?

8. Did any information you received affect decisions or lifestyle in any way? If so, how?

9. What information could you not find that would have been helpful?

10. Did you discuss your needs and the information you received with others? If so who?

11. Were you able to get information that was relevant for your family/friends/children/employer?

12. Once you knew the kind of MS your relative had did you need other kinds of information delivered in a different way? If so what?

13. Have you used the MS Trust's Information Service – did it meet your needs?

14. What could be done to improve information for people newly diagnosed with MS (prompts: access to information, format, content)

## Appendix 6 - face to face interview schedule

Introduce self. Explain purpose of interview. Check consent. Check they are willing to have interview recorded. Check if they are willing to be quoted (in unidentifiable form)

1. Could you tell me a bit about when you were first diagnosed with MS – in particular, what information you needed, and your experience of obtaining and using information?

Possible prompts:

a) What worked particularly well for you (in relation to meeting your information needs)?

b) What didn't work so well for you in relation to meeting your information needs?

c) Are there any particular formats of information that you preferred (e.g. leaflets, help lines, information from the internet etc).

2. Who was important to you as sources of information? (e.g. MS nurse, neurologist, voluntary sector etc)

3. Were you supported in any way to make use of the information you received? (prompt: for example, did you talk to a nurse about the information or ask them questions prompted by it, or did you talk to others with MS or use telephone help lines, email information services, support groups etc to support what you had learned?)

4. What about others close to you? Can you say anything about their needs for information? Were they the same as yours?

5. Did any of the information you received make a difference to what you do and how you live your life? if so, how?

6. For you, as a person newly diagnosed with MS, what do you think providers of information should be most aware of?

7. As time goes by, do you think your information needs and preferences are changing in any way? If so, how?

8. If you could go back over your experience of being newly diagnosed with MS:

- what would have made it easier for you to find and use the information you needed?
- What information would you have liked to have?

9. Anything else you would like to say?

## Appendix 7 - topic guide for focus groups

Introduce self and ask participants to introduce themselves

Explain about project; ask them all to respect each other's confidences; assure them we will not identify individuals. Explain we are digitally recording the group (and taking notes) but these records will be destroyed once the project is complete

1. When you were first diagnosed with MS, what was your experience of trying to get the information you needed?
2. What were the questions/issues most important to you at the time of diagnosis?
3. What worked well for you in trying to get information?
4. What did not work so well in trying to get information? (prompt: with the benefit of hindsight, were there any areas on which suitable information was not readily available to you? Would you have preferred information to be presented differently?)
5. Did anyone help you to find the information you needed? (for example your health professional, friends family, someone else with MS, The MS Trust or other organisation)
6. How relevant and appropriate was the information for your needs at that time?
7. Do you have any comments on the way in which information was offered (e.g. phone, website, leaflets etc)
8. Were you able to get information that was relevant for you in explaining MS to family/friends/children/employers etc?
9. Do you have any comments on the information needs and preferences of families and others close to people newly diagnosed with MS?
10. If you had to suggest two things that would bring about improvements in information for newly diagnosed people, what would they be? Perhaps you could suggest one thing about the content of information and one about how you get the information, or how it is presented to you?

## Appendix 8 - characteristics of interviewees and focus group participants

### Telephone interviewees (Tables 1 – 6)

Table 1 - Age and gender of all telephone interviewees (People with MS and family members)

(n=34)

	Male with MS	Male family member	Female with MS	Female Family member
18-25	0	0	1	0
26-35	2	1	8	2
36-45	2	1	3	1
46-55	0	2	6	0
56+	1	1	3	0
<b>Total</b>	<b>5</b>	<b>5</b>	<b>21</b>	<b>3</b>

Table 2 - Length of time since diagnosis for all telephone interviewees (People with MS and family members)

(n=34)

	Male with MS	Male family member	Female with MS	Female Family member
1-12 months	1	0	6	0
13-24 months	1	0	4	1
25-36 months	0	1	1	0
37-48 months	1	3	7	2
49-60 months	2	1	3	0
<b>Total</b>	<b>5</b>	<b>5</b>	<b>21</b>	<b>3</b>

Table 3 - Type of MS for all telephone interviewees (People with MS and family members)

(n=34)

	Male with MS	Male family member	Female with MS	Female Family member
Relapsing remitting	4	4	17	2
Primary Progressive	1	1	1	0
Secondary Progressive	0	0	1	0
Benign	0	0	1	0
Other	0	0	1 (RR or SP)	0
Don't know	0	0	0	1
<b>Total</b>	<b>5</b>	<b>5</b>	<b>21</b>	<b>3</b>

Table 4 – Self-reported ethnicity of all telephone interviewees (People with MS and family members)  
(n=34)

	Male with MS	Male family member	Female with MS	Female Family member
White British	1	5	11	3
British	2	0	2	0
White	0	0	1	0
White UK	0	0	1	0
White English	0	0	1	0
White German	0	0	1	0
White Welsh	0	0	1	0
English Caucasian	1	0	0	0
White other	0	0	1	0
White non-British	1	0	0	0
British Indian	0	0	1	0
Black Caribbean	0	0	1	0
<b>Total</b>	<b>5</b>	<b>5</b>	<b>21</b>	<b>3</b>

Table 6 – Place of residence of all telephone interviewees<sup>2</sup>  
(n=34)

Place of residence	People with MS	Family members
Anglesey	1	0
Antrim	1	0
Argyllshire	1	0
Berkshire	1	0
Cheshire	0	1
Clwyd	2	0
Devon	0	1
East Yorkshire	1	0
Gloucestershire	1	1
Kent	1	0
Lancashire	1	1
Leicestershire	2	0
London	4	2
Merseyside	1	0
Northamptonshire	1	0
North Yorkshire	1	0 (continued over page)

<sup>2</sup>We asked interviewees to state their county of residence. This resulted in some people giving local government areas, some giving towns and some giving geographical counties. Since the purpose of these tables is to show the geographical spread of interviewees, we have assigned all answers to geographical counties.

Oxfordshire	1	0
Shropshire	0	1
Somerset	1	0
Staffordshire	1	0
Stirlingshire	1	1
Tyne and Wear	1	0
Warwickshire	1	0
Worcestershire	1	0
<b>Total</b>	<b>26</b>	<b>8</b>

### Face to face interviewees (Tables 7 – 12)

Table 7 - Age and gender of all face to face interviewees (n=5)<sup>3</sup>

	Male with MS	Female with MS
18-25	0	0
26-35	0	1
36-45	0	1
46-55	1	2
56+	0	0
<b>Total</b>	<b>1</b>	<b>4</b>

Table 8 - Length of time since diagnosis for face to face interviewees (n=5)

	Male with MS	Female with MS
1-12 months	0	3
13-24 months	0	0
25-36 months	0	0
37-48 months	1	1
49-60 months	0	0
<b>Total</b>	<b>1</b>	<b>4</b>

<sup>3</sup> The partner of one of the interviewees joined in for a small part of the interview. His comments were noted but he has not been included in the total of the interviewees.

Table 10 - Type of MS of face to face interviewees  
(n=5)

	<b>Male with MS</b>	<b>Female with MS</b>
Relapsing remitting	0	3
Primary Progressive	0	0
Secondary Progressive	1	1
Benign	0	0
Other	0	0
Don't know	0	0
<b>Total</b>	<b>1</b>	<b>4</b>

Table 11 – Self-reported ethnicity of face to face interviewees  
(n=5)

	<b>Male with MS</b>	<b>Female with MS</b>
White British	1	3
British Indian	0	1
<b>Total</b>	<b>1</b>	<b>4</b>

Table 12 – Place of residence for all face to face interviewees<sup>4</sup>  
(n=5)

	<b>Male with MS</b>	<b>Female with MS</b>
Hertfordshire	0	1
Kent	1	0
London	0	1
Nottinghamshire	0	1
Somerset	0	1
<b>Total</b>	<b>1</b>	<b>4</b>

4 As footnote 2

## Characteristics of Focus group participants (tables 13 – 16)

Table 13 - Age and gender of all focus group participants (People with MS and family members)

(n=20)

	Male with MS	Male family member	Female with MS	Female Family member
18-25	0	0	1	0
26-35	0	0	1	0
36-45	4	1	7	0
46-55	0	1	4	0
56+	0	0	1	0
<b>Total</b>	<b>4</b>	<b>2</b>	<b>14</b>	<b>0</b>

Table 14 - Length of time since diagnosis for all focus group participants (People with MS and family members)

(n=20)

	Male with MS	Male family member	Female with MS	Female Family member
1-12 months	1	0	2	0
13-24 months	0	1	2	0
25-36 months	2	1	2	0
37-48 months	1	0	7	0
49-60 months	0	0	1	0
<b>Total</b>	<b>4</b>	<b>2</b>	<b>14</b>	<b>0</b>

Table 15 - Type of MS for all focus group participants (People with MS and family members)

(n=20)

	Male with MS	Male family member	Female with MS	Female Family member
Relapsing remitting	2	1	9	0
Primary Progressive	2	1	4	0
Secondary Progressive	0	0	0	0
Benign	0	0	0	0
Other	0	0	0	0
Don't know	0	0	1	
<b>Total</b>	<b>4</b>	<b>2</b>	<b>14</b>	<b>0</b>

Table 16 – Self-reported ethnicity of all focus group participants (People with MS and family members)  
(n=20)

	<b>Male with MS</b>	<b>Male family member</b>	<b>Female with MS</b>	<b>Female Family member</b>
White British	2	1	5	0
White	1	0	1	0
White Welsh	0	0	1	0
White English	0	0	1	0
British	0	0	2	0
Not disclosed	1	1	2	0
British Indian	0	0	1	0
Black African	0	0	1	0

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