Experiences of people using MS specialist nurse services
1. Introduction

This report documents the methods and results of a 2010 MS Society survey of people with MS who use the services of an MS specialist nurse. MS specialist nurses play a vital role in the care and support of people with MS, but despite this many of these posts across the UK are under threat. This survey was designed by the MS Society Research team and Service Development team, with the aim of gathering experiences and opinions of people with MS about the MS specialist nurse service they receive.

The survey had two sections; the first part asked some background information and questions about contacting the specialist nurse. The second part of the survey focused specifically on people’s experiences of the service they receive. This section was organised around themes linked to identified good practice cited in numerous policy documents. ‘Good care’ is defined as being person-centred: rather than patients being the passive recipients of care, care is now expected to be founded on a partnership between people who have a certain condition, clinicians and other relevant agencies. This requires people with MS being empowered to make informed decisions about their care and actively managing their own conditions with the right support and information made available to them. These aspects of care were reflected in the themes ‘Getting information’, ‘Your care’, ‘Independence and self-management’ and ‘Access and availability’ in the second section.
1.1. What is MS and what care is needed?

MS is the most common disabling neurological condition affecting young adults. There are around 100,000 people in the UK living with MS. MS is the result of the body’s own immune system attacking and damaging myelin – a protective substance surrounding nerve fibres of the central nervous system. When myelin is damaged, messages between the brain and other parts of the body are distorted or lost. Over time, in addition to myelin damage, the nerve fibres themselves also become damaged leading to an irreversible accumulation of disability.

Different types of MS

There are three broad types of MS, each with its own characteristics and specific care needs. Regardless of the type, some people may be only mildly affected throughout their lives, while for others the effects may become quickly noticeable and more severe. Most people with MS experience something in between these extremes. It is not always clear what type of MS someone has, particularly when newly diagnosed, and regardless of the type, health professionals will base symptom management and tailor treatments to the needs of each person.

Relapsing remitting MS

Most people (around 85 per cent) are first diagnosed with relapsing remitting MS. This means they experience a relapse or flare-up of symptoms (also known as an attack or exacerbation) followed by remission (a period of recovery). Relapses usually take a few days to develop and can last for days, weeks (most commonly) or months, and can vary from mild to severe. Remission can also last for many months or years. In the early stages of relapsing remitting MS, symptoms can disappear completely during remissions. However, after several relapses there may be more residual damage to the myelin and nerve fibres, resulting in only a partial recovery.

Secondary progressive MS

Most people who start out with relapsing remitting MS later develop a form of MS that is known as secondary progressive. In secondary progressive MS, symptoms do not go away completely after a relapse and there is a steady increase in disability. This progression can be very slow and changes may be so slight that they are hard to notice for a long time. Around 65 per cent of people with relapsing remitting MS will have developed secondary progressive MS within 15 years of being diagnosed.

Primary progressive MS

Primary progressive MS is a less common form of MS – affecting around 15 per cent of people diagnosed. From the beginning, those with primary progressive MS experience steadily worsening symptoms and an increase in disability over time instead of sudden attacks or relapses. Symptoms may level off at any time, or may continue to worsen.

What is a relapse?

A relapse is an episode of neurological symptoms caused by inflammation or demyelination that happens at least 30 days after any previous episode began, lasts at least 24 hours and is not the result of an infection or any other cause.

Relapses are caused by inflammation in the central nervous system (the brain and spinal cord). This inflammation is the body’s reaction when immune cells mistakenly attack the protective layer (myelin) that surrounds nerve fibres. A relapse can also be called an attack, exacerbation, flare-up, acute episode or clinical event.
In a relapse, new symptoms appear, or old symptoms re-appear, either gradually or suddenly. Symptoms usually come on over a short period of time – hours or days, and can last from a few days to many months. This uncertainty can be difficult to deal with, and support and help is needed to manage not just the physical relapse but emotional aspects of it as well. MS nurses can provide this support.

Relapses need to be recognised quickly so that an intervention can be delivered as early as possible. Steroid therapy can be given to reduce the inflammation, shorten the duration of the relapse and speed up recovery.

**Symptoms in MS**

MS can be very unpredictable. People can have different symptoms at different times and, although some are very common, there is no typical pattern that applies to everyone. Many people experience only a few symptoms and it is unlikely that anyone will develop them all. Symptoms can occur randomly – at any time, and in any order. They may last for a few hours, or for days, weeks or even months. To complicate things further, not all symptoms experienced by someone with MS will be caused by their MS; they could be caused by something else entirely.

Some common symptoms are listed below:

- Difficulties with balance and dizziness
- Fatigue - an overwhelming sense of tiredness
- Visual problems such as blurred or double vision
- Numbness, tingling or pins and needles - sometimes these sensory changes can feel painful
- Bladder problems
- Cognitive problems (problems with memory and thinking)
- Stiffness or spasms in muscles - sometimes called 'spasticity'
- Emotional and mood changes
- Tremor
- Bowel problems
- Sexual problems
- Speech and swallowing difficulties

Some symptoms, such as walking difficulties, are obvious to other people. Others, such as pain or fatigue, are not and are often referred to as hidden, invisible or silent symptoms. Hidden symptoms may be more difficult to understand, for those unfamiliar with MS. MS nurses can help the person with MS to understand their symptoms and their condition better.
Treatments

There are different ways to tackle the problems caused by MS. Many MS symptoms can be managed using a variety of treatments and specialist support.

Disease modifying drugs (DMDs) are used to reduce the number and severity of relapses but do not stop disability progression. There are four classes of DMDs currently licensed for relapsing remitting MS and none for primary progressive MS or secondary progressive MS. Those licensed for relapsing remitting MS are: beta interferon 1a, beta interferon 1b, glatiramer acetate and natalizumab.

The beta interferons and glatiramer acetate are delivered by self-injection (under the skin or into the muscle) at frequencies ranging from once daily to once weekly. Natalizumab is delivered by monthly infusion in a hospital clinic. The side effects and difficulty in taking these treatments mean that the support of a specialist is vital.

Specialists, such as occupational therapists, physiotherapists, continence advisers and psychologists, can help with mobility, coordination, continence, and memory or concentration problems. These are services that people with MS can discuss, for example, with their specialist nurse who can help to identify the best therapies available.

Care, support and advice

Dealing with the multiplicity of MS symptoms, drugs and treatments requires specialist knowledge of MS so that care can be adjusted to meet individual needs. However, the support needs of people with MS are not only limited to dealing with the physical symptoms - having MS means living with uncertainty and adapting to changing situations. Adapting to life with MS can take time, and the appropriate support, care and information is often key to enable people to manage their condition well.

From adjusting to a new diagnosis, to managing the stresses of day to day living with MS, it is crucial that people with MS have the right care and support at their disposal. Providing the right information is key to supporting people with MS to manage their condition. MS specialist nurses are ideally placed to deliver care and support that can adjust to the fluctuations of MS. Based on their specialist knowledge, gained from research evidence as well as from practice, specialist nurses can tailor care to individual needs.

Policy environment

‘Good care’ is defined as being patient-centred: rather than patients being the passive recipients of care, care is now expected to be organised as a partnership of people with MS, clinicians and other relevant agencies. This requires enabling people to make informed decisions about their care and actively manage their own conditions with the right support and information made available to them.

In an attempt to improve the standard of care of those affected by long-term neurological conditions, the previous government launched a 10-year initiative, the National Service Framework for Long-term Conditions, in 2005. The key themes of the National Service Framework (NSF) are independent living; care planned around the needs and choices of the individual; easier, timely access to services and joint working across all agencies and disciplines involved\(^1\). The NSF is framed around 11

\(^1\) Department of Health (2005): National Service Framework for long-term conditions
quality requirements which outline the expectations of standards throughout the care pathway.

As a result of the recent change of government, the policy context in healthcare has altered significantly. The white paper, *Equity and Excellence: Liberating the NHS*\(^2\), outlines the government’s long-term plans for the NHS. The white paper puts the patient firmly at the centre, focusing on more personalised care, supporting patients to be in control of their own care, and involving people in decision-making about the way healthcare services are delivered.

The Department of Health (DH) has recently published the NHS Outcomes Framework\(^3\), which has been “developed to provide that national level accountability for the outcomes that the NHS delivers” (2010). The framework highlights some key areas for improvement in the care of people with long-term conditions, for example ensuring that people feel supported to manage their condition.

It is still too early to say how the outcomes framework will affect the delivery of care at a local level. However it can be assumed that the central themes captured in the NSF remain valid to the care of people with neurological conditions such as MS. As such, the design of the survey was informed by these key themes and this is reflected in the statements under the headings ‘Getting information’, ‘Your care’, ‘Independence and self-management’ and ‘Access and availability’. The statements included in the questionnaire were selected as ones where there is potential for an MS specialist nurse to have an impact.

---

\(^{2}\) Department of Health (2010): Equity and excellence: Liberating the NHS

\(^{3}\) Department of Health (2010): NHS Outcomes Framework
1.2. Administration and analysis of the survey

The survey was available online, at surveymonkey.com, from 28 October until 12 November 2010 and was advertised on the MS Society website. Information and a link to the survey were posted on the MS Society’s Facebook page, which has 8000 fans, and sent to 3000 Twitter followers.

People who had MS, who were over the age of 16 and who had been in contact with a MS specialist nurse in the past 12 months, were invited to take part in the survey. There were a total of 969 fully completed surveys included in the analysis.

The average respondent was female (72 per cent), aged between 31 and 50 (61 per cent), and had relapsing remitting MS (60 per cent). Figure 1 and figure 2 show the distribution of age and type of MS. The majority of respondents lived in England (89 per cent), with a further 7 per cent from Scotland, 2 per cent from Wales and 1 per cent from Northern Ireland.

![Figure 1](image1.png)

**Figure 1**

![Figure 2](image2.png)

**Figure 2**
Analysis
Descriptive statistics were used to analyse the results of the survey. Due to rounding, the percentages for each question do not always add up to 100 per cent. Quotes from the free comment sections were extracted to illustrate the results of the survey, but no systematic analysis was conducted on the free text answers.
2. Contacting your MS specialist nurse

The purpose of the second section of the questionnaire was to find out some general information about the types of contact respondents had with a specialist nurse. The intention was to specifically look at the experiences of those who had had contact with a nurse and access issues were left outside of the remit of the questionnaire.

All those who met the inclusion criteria were first asked how many times in total they had had contact with their specialist nurse in the past 12 months. The results of this question are shown in figure 3.

![Figure 3](image-url)

In the last 12 months, how many times have you had contact with your MS specialist nurse?

- 1-2: 36%
- 3-4: 36%
- 5 or above: 28%
Respondents were then asked to identify all of the different methods by which they had received support from their MS specialist nurse in the previous 12 months. The most commonly used method was by telephone (75 per cent of respondents) followed by at a specialist clinic (70 per cent). The results of this question are shown in figure 4.

Respondents were then asked to select only one option as the most common method by which they had received support from their MS specialist nurse. Here the most common method (44 per cent) was ‘at a specialist clinic in a hospital setting’ and the least common was ‘by email’ (7 per cent). Although the majority of respondents did make use of the telephone to contact their nurse for most seeing their nurse face-to-face remains the most frequent way to contact them. The results of this question are shown in figure 5.
In the last 12 months, what has been the most common way you have received support from your MS specialist nurse?

<table>
<thead>
<tr>
<th>Method of support</th>
<th>Percentage of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>At a specialist clinic in a hospital setting</td>
<td>44%</td>
</tr>
<tr>
<td>By telephone</td>
<td>31%</td>
</tr>
<tr>
<td>The nurse visiting your home</td>
<td>10%</td>
</tr>
<tr>
<td>At an outreach clinic in a community setting</td>
<td>9%</td>
</tr>
<tr>
<td>By email</td>
<td>7%</td>
</tr>
</tbody>
</table>

**Figure 5**

The last question mapped specific reasons for contacting a nurse outside of prearranged appointments. Again, it was possible to select all options that applied. Most commonly (61 per cent of all respondents), the reason for contact was ‘to discuss a relapse, new/ worsening symptom or a sudden change in health’. Other common reasons included ‘to discuss your medication’ (49 per cent) and to ‘discuss possible treatment options’ (37 per cent). Only (14 per cent) of respondents chose ‘I have not needed to contact my MS specialist nurse outside of prearranged appointments.’ The large majority had contacted the nurse outside of prearranged at least once. Overall, the responses to the question demonstrate that the specialist nurses provide an invaluable safety net for people who live with an unpredictable long-term condition. The results of this question are shown in figure 6.

In the last 12 months, outside prearranged appointments, have you contacted your MS specialist nurse specifically to:

<table>
<thead>
<tr>
<th>Reason</th>
<th>Had contacted their nurse for this reason</th>
<th>Had not contacted their nurse for this reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss a relapse, new/worsening symptom or a sudden change in health</td>
<td>61%</td>
<td>39%</td>
</tr>
<tr>
<td>Discuss your medication</td>
<td>45%</td>
<td>55%</td>
</tr>
<tr>
<td>Discuss possible treatment options</td>
<td>37%</td>
<td>63%</td>
</tr>
<tr>
<td>Get some general information about MS</td>
<td>24%</td>
<td>76%</td>
</tr>
<tr>
<td>Receive emotional support</td>
<td>25%</td>
<td>75%</td>
</tr>
<tr>
<td>I have not needed to contact my MS specialist nurse outside of prearranged appointments</td>
<td>14%</td>
<td>86%</td>
</tr>
</tbody>
</table>

**Figure 6**
3. Statements related to experience

The second part of the questionnaire looked into the experiences of people with MS who are in contact with a specialist nurse service. In this section the respondents were presented with statements related to different aspects of care and asked to rate how closely the statements reflected their experiences. The response options were ‘always’, ‘often’, ‘occasionally’ and ‘never’.

The statements and response categories were designed to map respondents’ perceptions of service where they had used it, rather than provide an absolute measure to see whether or not service was available. For example, the response category ‘never’ can also include those who have not needed a service, rather than the never category being indicative of the service not being available or being offered. Overwhelmingly, respondents recognised the importance of MS specialist nurses as presented in the statements and felt that the nurses were key in supporting them in these areas. All of the results for the statements are shown in figures 7 -12.

The statements were categorised under the broader themes of ‘Information provision’, ‘Care’, ‘Independence and self-management’ and ‘Access and availability’. These themes were chosen as ones that represented the ideals of person-centred care and where there was a potential to link with the care and services provided by MS specialist nurses. The categories and statements were further influenced by ideals of care as expressed in policy documents, such as the health white paper or the National Service Framework.

Although the different themes are neatly separated for the purposes of the questionnaire and this report, it’s clear that the domains of activity represented here are often interlinked in practice: information provision is intertwined with decision-making; the prerequisite for self-managing a condition is the right support and independence is built on a foundation set by all these areas. All in all, in the real world the different themes overlap and this is conveyed in the experiences of people given in the open responses where a picture emerges of an MS specialist nurse skilfully tailoring care to meet the individual needs of a person with MS.

The rest of this report will look in more detail into some of the statements and the open responses.
3.1. Information

“Information, combined with the right support, is the key to better care, better outcomes and reduced costs. Patients need and should have far more information and data on all aspects of healthcare, to enable them to share in decisions made about their care and find out much more easily about services that are available.”

Equity and excellence: Liberating the NHS

Information provision has become an undisputed part of care, as demonstrated in the recent white paper as well as other policy documents. The person at the centre of care needs information if they are to make informed choices related to their own care and treatment, thereby enabling them to manage their condition. Access to relevant and accurate information then becomes paramount. One aspect of the specialist nurse’s role is being an educator, as outlined by Porter\(^4\), making them ideally placed to provide information.

The questionnaire sought to find out how people with MS experienced the information provision by their nurses. To this end, the respondents were presented with statements about gaining information from their MS specialist nurse about current medication, treatment, symptoms and care options. The results of this question are shown in Figure 7.

*Figure 7*

Overall, the majority of respondents’ experiences were that their nurse was ‘always’ or ‘often’ of help when they wanted information in any of these areas, with over 60 per cent of the respondents feeling that their specialist nurse ‘always’ helps them when they want to know about different treatments, or their current medication.

Timely information about medication can be crucial in MS, for example, so that a steroid treatment can be started promptly when needed:

‘When I last had a relapse I spoke to her [nurse] first and she advised me what to seek from my GP appointment and used the information to enable me to access IV drugs without having an extra appointment with the neurologist, which saved his time and speeded up treatment.’

‘I had very frequent relapses in the past and my MS nurse would always arrange for me to be seen for treatment as soon as possible. When the frequency got worse she talked me through the second line treatment options so that I understood them when I discussed them with my Neurologist.’

Asking about symptoms appeared to be an important area, where 69 per cent of respondents took the view that their nurse ‘always’ provides information when sought on this subject.

MS symptoms can change and fluctuate and being able to discuss symptoms with one’s nurse is also important so that changes in the condition can be identified and dealt with appropriately:

‘I suddenly felt connected at last to someone who could assure me about continuing symptoms and how to distinguish a relapse from these changeable, but continuous symptoms. My MS nurse took the time to fully explain M.S, in a way that the neurologists could not, in their very brief appointments.’

‘I rely on my MS nurse as a first point of contact whenever I am experiencing new symptoms or I am worried about a relapse coming on. She always advises me on what needs to be done and puts my mind at ease.’

As the open responses show, the specialist nurses have a key role in information provision, and in doing so, also allaying fear and worry. Through information provision nurses also support people with MS in learning a new self-awareness to understand and monitor their symptoms.

Overall, the nurses’ role as key information providers came up frequently in the open responses and illustrated how nurses provide information throughout the care trajectory, from diagnosis:

‘On my initial diagnosis my MS nurse sat with me and my husband and spent a lengthy time going through all of our worries and where we could go for help and support. I have also attended three sessions for newly diagnosed people organised by the MS nurses which was fantastic.’

‘When you receive a diagnosis of MS you feel like it is the end of everything, my nurse has helped to show me that there are things that can be done and support is available.’

through acute situations,

‘My GP was not up to speed with the latest treatment for my last relapse. The MS specialist nurse was able to inform him about the preferred treatments.’

‘My MS nurse has helped me so much with my recent relapse, I don’t know what I would have done without her. Just having someone to talk to who understands and can give you the proper help that you need.’
‘I would feel completely isolated in my MS without the knowledge that I can get to talk to my MS nurse within a matter of hours. She has got me through some fairly horrific relapses and has been absolutely critical in the management of the disease.’

to providing information for on-going support:

‘I cannot imagine how living with active relapsing remitting MS would be without the support of the MS specialist nurses. Before I had access to the MS nurses the only option on many occasions was to go to A&E which, in itself, is very stressful. Having the knowledge that I can always contact the MS nurses and that they are very efficient and professional means that I can wait to speak to them, safe in the knowledge that they will be able to deal with my situation totally appropriately and takes a great deal of the worry out of every situation.’

Interestingly, the nurses’ information provision does not only benefit people with MS and their carers, but also other health professionals, such as GPs:

‘My GP is a very good Dr but does not really understand my MS, and often asks me what the MS nurse has recommended or has rung her for advice on my treatment.’

‘I rarely have contact with my neurologist except for arranged appointments and he is difficult to get hold of. Having someone specialist in the field who can advise me and my GP is incredibly important. I don’t know what I would have done during my last relapse if I had not been able to contact my nurse.’
3.2 Care

“The system will focus on personalised care that reflects individuals’ health and care needs, supports carers and encourages strong joint arrangements and local partnerships.”

Equity and excellence: Liberating the NHS

The second set of statements scoped different aspects of care provided by an MS nurse. The statements around the care theme sought to find out about respondents’ experiences on having one point of contact and coordination of care, support on decision making, support to family and carers, as well as advice and help to access other care services. The ideal care is viewed as something striving towards a partnership, rather than something delivered top-down and passively received. Care provision, therefore, should take more collaborative forms than in the past.

Coordination and first point of contact

To deliver care as a partnership, better coordination across different agencies and professional boundaries is needed. Cooperation of various professionals is especially important in meeting the changing needs of people with MS. The variety of services needed by people with MS and the different agencies involved can easily overwhelm anyone, and good care coordination and having a one point of contact is therefore vital.

The role of the nurse as a central point of contact to individuals, as well as a ‘lynchpin’ with connections to different services became apparent in the statements as well as the open responses. The results of these questions are shown in figure 8.

Your Care
My MS specialist nurse:

- Helps me to take my medication correctly
- Is my first point of contact if I have any questions about my MS
- Refers me to other professionals when needed
- Advises me on different care and support services available
- Helps me to access different care and support services available

<table>
<thead>
<tr>
<th>Service</th>
<th>Always</th>
<th>Often</th>
<th>Occasionally</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helps me to take my medication correctly</td>
<td>46%</td>
<td>20%</td>
<td>19%</td>
<td>15%</td>
</tr>
<tr>
<td>Is my first point of contact if I have any questions</td>
<td>71%</td>
<td>20%</td>
<td>7%</td>
<td>2%</td>
</tr>
<tr>
<td>about my MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refers me to other professionals when needed</td>
<td>70%</td>
<td>13%</td>
<td>14%</td>
<td>3%</td>
</tr>
<tr>
<td>Advises me on different care and support services</td>
<td>54%</td>
<td>23%</td>
<td>15%</td>
<td>8%</td>
</tr>
<tr>
<td>available</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps me to access different care and support services</td>
<td>53%</td>
<td>22%</td>
<td>17%</td>
<td>9%</td>
</tr>
</tbody>
</table>
Over 70 per cent of respondents stated that their MS nurse is ‘always’ the first point of contact when they have any questions about their MS, with a further 20 per cent reporting this was the case ‘often’:

‘My MS nurse is always my first point of contact. They then help me to decide whether I need to see my GP or neurologist or whether I can manage without an intervention.’

‘My MS nurse is always my first point of contact before referral to treatment. I feel I can always call on her for advice about my symptoms and for general support when a visit to see a consultant or doctor is not always necessary.’

As the responses demonstrate, the nurse often acts as a gatekeeper, evaluating the need for help and ensuring a response is in proportion to need.

Having the nurse as a first point of contact was often juxtaposed with experiences of contacting a neurologist or a GP – neurologists who were thought simply to be too busy and well-meaning GPs who just don’t have the expertise:

‘My GP is a very good Dr but does not really understand my MS, and often asks me what the MS nurse has recommended or has rung her for advice on my treatment. If I have a relapse she is the person I call for advice before seeing my GP.’

‘Although my GP has been a great help to me, he is not an expert in MS and I often have had to go to him and ask him to prescribe me something that my MS nurse has suggested.’

‘My MS Nurse has been my number 1 contact for all my health issues, even my local Dr has told me to use the MS Nurse as they know more about MS than my Dr does.’

‘I find my MS Nurse invaluable as it is quite difficult to see the Neurologist as he is very busy. My MS Nurse if usually my first point of contact and as this disease is very unpredictable it is very reassuring to know that there is someone at the other end of the telephone whom I can contact and speak to.’

Other care & support services and referrals

As people with MS can have a variety of changing care needs, it is likely that care will be provided by a variety of different agencies. Respondents were presented with a statement “My specialist nurse refers me to other professionals when needed” and were asked to select the option that best reflected their experience. 83 per cent of respondents felt their nurse refers them to other professional when needed either ‘always’ or ‘often’. Another statement further scoping this theme was “My MS nurse helps me to access different care and support services available”, with nearly 60 per cent getting this help from their nurse ‘always’.

The open responses illustrated the full spectrum of specialist help needed by PwMS and how those needs were met through the service provided by a specialist nurse:

‘It is because of my MS nurse that I am still working and living life fully as possible. She has referred me for physio, continence management and counselling all of which would have been difficult to discuss and access in one 10 minute appointment with a consultant once a year.’
'After many years of difficulty in accessing a consultant for help, a new GP to my surgery referred me to the local MS nurses. They immediately suggested changes in medication, arranged physiotherapy, and continence advice, which eased months of suffering, and enabled me to return to work.'

Furthermore, it is evident that having the variety of help can have very tangible outcomes – it can enable either returning to or remaining in work.

**Decision-making**

The partnership in care should not only be limited to a collaboration between various professionals. In person-centred care, the person with MS should become a partner in their own care-planning and related decision-making.

Rethinking care as a collaborative action and moving away from top-down thinking requires a profound culture change and the white paper promises to make shared decision-making the norm as evidenced in the slogan: “No decision about me without me”.

So that people can fully participate in the decision-making related to their own care, they need the right information and support. With their specialist knowledge, role as information providers, and knowledge of the individual patient and their situation, MS nurses are ideally placed to facilitate shared decision-making. The respondents to this survey were presented with two statements related to decision-making: “My MS nurse involves me in decision making related to my own care” and “My MS nurse helps me to make informed decisions about my care”. The results of these questions are shown in figure 9.

---

**Your Care**

My MS specialist nurse:

- **Always**
- **Often**
- **Occasionally**
- **Never**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Percentage of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involves me in decision making related to my own care</td>
<td>Always: 62%</td>
</tr>
<tr>
<td></td>
<td>Often: 19%</td>
</tr>
<tr>
<td></td>
<td>Occasionally: 11%</td>
</tr>
<tr>
<td></td>
<td>Never: 8%</td>
</tr>
<tr>
<td>Helps me to make informed decisions about my care</td>
<td>Always: 62%</td>
</tr>
<tr>
<td></td>
<td>Often: 19%</td>
</tr>
<tr>
<td></td>
<td>Occasionally: 11%</td>
</tr>
<tr>
<td></td>
<td>Never: 8%</td>
</tr>
<tr>
<td>Provides support and advice to my family and carers</td>
<td>Always: 41%</td>
</tr>
<tr>
<td></td>
<td>Often: 19%</td>
</tr>
<tr>
<td></td>
<td>Occasionally: 8%</td>
</tr>
<tr>
<td></td>
<td>Never: 21%</td>
</tr>
<tr>
<td>Can adjust my care around any changes in my MS</td>
<td>Always: 49%</td>
</tr>
<tr>
<td></td>
<td>Often: 19%</td>
</tr>
<tr>
<td></td>
<td>Occasionally: 18%</td>
</tr>
<tr>
<td></td>
<td>Never: 14%</td>
</tr>
</tbody>
</table>

---

5 Department of Health (2010): Equity and excellence: Liberating the NHS
Again, overwhelmingly the respondents felt their nurse was helping them in these areas, with over 80 per cent stating their nurse helps and involves them in decision-making either ‘always’ or ‘often’:

‘When I am struggling to make decisions she always has an alternative view to help me with the decisions, she is so supportive.’

‘She is someone who is on my side and asks me what I want not what everyone is telling me I should do or what they think is best. She asks what I want, she is probably the only one who does.’

Overall, the most straightforward seeming decisions have unexpected ramifications when someone has a long-term condition. Starting a family is a big step for anyone, but for someone with MS this decision becomes intertwined with the complexities of the condition and a situation where having the right support in decision-making is of paramount importance:

‘When first diagnosed they [MS nurses] were unbelievably helpful, especially at giving me an honest insight into what I was facing. They have also been brilliant at talking me through medication and my choices regarding having a family. In fact, I am now pregnant with my first child - a decision made easier by the information they had for me.’

Open responses also paint a picture of MS specialist nurses as interpreters and intermediaries between the person with MS and health professionals. The examples here show the MS nurse facilitating the very partnerships valued in the white paper:

‘I always have my nurse with me in appointments with my neurologist to support me and explain things to me. There have been times when my nurse has highlighted my feelings as a patient when my neurologist has overlooked this part of me as a patient- sometimes my neurologist almost forgets I am a person and not just a collection of worsening symptoms! My MS nurse always gets me to speak up in appointments about my views on how I am feeling and how things are rather than just allowing my neurologist to assume he knows that from test results alone- my MS nurse makes sure the patient is seen and treated as a person and also understands the value of the patient knowing their own condition better than anyone else.’

‘I see my consultant regularly and my MS Nurse always attends the appointment and spends time with me after to ensure any questions I have are fully answered.’

Shared decision-making is somewhat of a culture change in the health care setting and this change needs to be actively managed. MS specialist nurses are doing important translational work to make the world of the clinic meet the everyday life of a person with MS.
Supporting family and carers

The impact of a long-term condition such as MS is not only limited to the person who has the condition, but goes far wider. The white paper recognises the role of carers as an integral part of person-centred care and thereby the need for wider support. Respondents were asked about their experiences of their nurse supporting also families and carers.

With 41 per cent responding their nurse provides support also to family and carers 'always' and a further 19 per cent considering this to be the case 'often', this statement did not seem to reflect an experience as universally shared as some of the other statements. Nevertheless, a staggering 80 per cent has found their nurse to provide support to family and carers at some point and this came vividly across in the open responses:

‘She always has time to discuss anything I need to, and spends time and finds resources for my children to help understand M.S and discuss their reservations.’

‘She always involves the whole family when she visits. Seeing if my wife is coping and our daughter is ok with everything and understands what’s going on.’
3.3. Independence and self-management

Overall, the direction of care has been moving towards supporting people to remain independent and to enable them to manage their conditions themselves to the extent this is possible. In the current government’s policy, this has been articulated in the NHS Outcomes Framework, where one of the improvement areas is to ensure people with long-term conditions feel supported to manage their condition.

The themes discussed in the earlier sections, ‘Information’ and ‘Care’, form the foundation of independence. Having the right information, supported and shared decision-making all contribute to the empowerment of the person with MS, enabling them to remain independent and take more control over the management of their condition.

In this section, respondents were presented with statements scoping how their nurse supports them to remain independent.

Understanding MS and taking care of oneself

Getting to grips with a diagnosis of MS can take time, and often means learning to be more receptive to one’s own physical well-being in the context of the condition. Support is needed not only in the adjustment phase but also later due to the variable nature of MS. The statements in this section asked about the support from a nurse and how this helps people to understand their own MS and to take care of themselves. The results of these questions are shown in figure 10.

![Independence and self-management](image-url)

*Figure 10*
The majority of respondents felt that the support from a nurse ‘always’ helped them to understand their condition (73 per cent) and helped them to take care of themselves (63 per cent):

‘She makes me look at what I consider a huge problem in a way that I can cope with it.’

‘As a recently diagnosed person, the support offered to myself and my family by the specialist nursing team has been invaluable. It has helped us to acclimatise to this new aspect of our lives and taken away any irrational fears. I feel supported and I know that if I have any questions, concerns or issues they are there to answer my needs. Dealing with a life changing illness like MS is frightening and knowing there are people there who understand your feelings and the weird nature of this particular disease makes is significantly easier to deal with.’

Respondents were also asked whether they felt the support from their nurse helped them to keep independent and active. Around 70 per cent of respondents felt that this was the case ‘always’. The results of these questions are shown in figure 11.

Independence and self-management
The support I receive from my MS specialist nurse:

![Bar chart showing the percentage of respondents who feel the support from their nurse helps them to be as independent as they can be, remain as active as they can be, maintain their quality of life, and manage an oncoming relapse or a new/worsening symptom.]

Figure 11
Many of the respondents elaborated on the meanings of remaining ‘independent’ or ‘active’ in the open responses. For many this meant nothing less than the ordinary activities of everyday life that most people would take for granted.

Remaining active and independent could mean anything from staying in the workforce:

‘She recently spoke to my employers to help them understand about fatigue so I can get the best out of my working day.’

‘Having an ms nurse has enabled me to remain in work and cope well with the condition. I don’t worry about the condition as I know any concerns can been soon sorted. It is great to have a familiar face who knows who you are and someone who can help you make very important decisions.’

‘Having a Nurse has helped me return to employment, have a life and feel alive again. This very valuable resource has helped me to have MS and not MS to have me.’

.. to just living an ordinary life:

‘I actually can’t imagine what life with MS would be like without the support of the MS nurses that are available to me. Having their support is what enables me to live a relatively ’normal’ and independent life.’
3.4. Access and availability

Finally, the respondents were presented with statements about accessing the specialist nurse service. Once again, this aspect of the service was perceived very positively. The results of these questions are shown in figure 12.

Figure 12

The majority of respondents (69 per cent) felt that it was easy to contact a specialist nurse ‘always’. This may be also partly due to the various methods of contact available, discussed on page 8 and demonstrated in figure 4. The ease of contact was also elaborated in the open responses:

'Whenever I give my name on the telephone they know who I am and the problems I have with my MS. I feel this personal contact is very important as it encourages me to speak more openly about any issues I have. '

'It is helpful to know there is someone at the end of a phone that is always available to give assistance if needed.'

'I love the fact my MS nurse is at the end of the phone or even only a text message away on the odd occasions I have needed to see her sooner than a routine appointment.'
Although it was felt that it is fairly easy to contact a specialist nurse overall, the proportion of respondents feeling that they can ‘always’ see their nurse when they need to was somewhat lower (49 per cent) than in other statements in this section. Many open responses also showed that people are well aware of the workload of the nurses and the financial pressure on the service:

‘I find my MS nurse an invaluable asset. The only problem is that she is very, very busy and so not always able to get back to me as quickly as she would like. We need MORE not less of them!’

Reflecting the awareness of the workload, some respondents were careful to emphasise that while the knowledge of having the support is important, they would only contact the nurse when their need was real:

‘My MS nurse is a lifeline - I only contact her when I am concerned about my condition or need help with medication, but she has always been extremely helpful and supportive.’

‘They all know my history and treatment/drug history. All are highly knowledgeable and skilled in recognising when I need help from them or referral to other [people affected by MS]. Frankly this is an essential service. Not a luxury.’

With the pressures of living with a long-term condition, it is vital that support can be easily accessed. 69 per cent of respondents felt that they can contact the nurse even for small problems:

‘She is always there when I need her, and no problem is ever viewed as "silly" or as if I'm worrying too much, and she is also there if my mum has any questions she needs to ask.’

‘You do not feel inhibited to raise "silly little" problems with them that you feel you should not "bother" a Neurologist with.’

This ease of contacting was further illustrated in some responses drawing attention to some MS symptoms that can be socially difficult to deal with:

‘There are a lot of embarrassing problems with MS and the MS Nurses are always there with a listening ear and lots of care and understanding as well as problem solving.’

‘They are more able to talk to you as a real person, not a patient, and I feel much more comfortable discussing some of the personal effects/problems that surround my MS, with them, than I do with my consultant.’

Interestingly, many respondents brought up the importance of knowing there is support available - just the knowledge of having the nurse available was felt reassuring:

‘She is very approachable and honest in her responses to my questions and concerns. Knowing that there is someone available, who will support me when I need it, is helping me to manage this debilitating condition.’
4. Conclusion

All in all, the responses showed that the nurse service was very highly valued by people with MS. The statements in the questionnaire scoped different domains of nurse activities and people’s view of them. From the perspective of people with MS, MS nurses deliver the kind of service that enables people with MS to manage their own condition, allows them to form partnerships with health care professionals and take ownership of their own care – exactly as in the ideals outlined in policy documents.

There was a lot of interest in the survey and respondents expressed their genuine concern for what would happen if they did not have the support of their specialist nurses. The responses to the survey and the stories people with MS told, portrayed a service that provides the flexibility, responsiveness and high quality needed to support people with a variable condition such as MS. Not only do the MS nurses provide high quality care as this understood in policy documents, but they also provide the vital aspects of care that aren’t easily captured in outcome measures, or cannot be counted in numbers. MS nurses, then, provide no less than “the human face of the NHS”, as elaborated by one of the respondents:

‘The MS nurse is the 'human face' of the NHS. Doctors are excellent, but it is the nurse who can take the time to get to know individuals, to explain symptoms and treatments. For me, when frightening first diagnosis was made, it was the MS nurse he was able to bring back some perspective and reassurance for me and my loved ones. Without the nurse, having MS could be frightening and lonely, not just for me but for my partner and relatives. She provides reassurance and her experience inspires confidence.’
5. Appendix 1- Questionnaire

### Experiences of people using MS specialist nurse services

#### 1. Welcome

The purpose of this survey is to capture the experiences of people with MS who currently use MS specialist nurse services.

The information collected from this survey will be used to inform MS Society service development and campaigning work both nationally and locally.

We would like to invite those people with MS who currently use the services of an MS specialist nurse to take part in this survey. Unfortunately, people who do not currently use these services will not be included.

Any information you submit will be treated as confidential and will be anonymised so that it will not be possible to identify any individual persons from any results. Participation is voluntary and you are free to stop completing the survey at any time if you wish to.

If you have any questions please contact servicedevelopment@mssociety.org.uk

Thank you very much for your time.

#### 2. General information about you

**1. Do you have MS?**
- [ ] No, I do not have MS
- [ ] I have relapsing remitting MS
- [ ] I have primary progressive MS
- [ ] I have secondary progressive MS without relapses
- [ ] I have secondary progressive MS with relapses
- [ ] I have MS but I do not know which type

**2. Have you had contact with an MS specialist nurse in relation to your MS, in the last 12 months?**
- [ ] Yes, I have had contact with an MS specialist nurse
- [ ] No, I have not had contact with an MS specialist nurse
- [ ] I don't know if my health professional is an MS specialist nurse
### Experiences of people using MS specialist nurse services

3. How old are you?
- Under 16
- 16-30
- 31-50
- 51-65
- Over 65

### 3. General information about you (continued)

1. Are you male or female?
- Male
- Female

2. Where do you currently live?
- England
- Scotland
- Wales
- Northern Ireland

### 4. Contacting your MS specialist nurse

1. In the last 12 months, how many times have you had contact with your MS specialist nurse?
- 1-2
- 3-4
- 5 or above

2. In the last 12 months, by which of the following methods have you received support from your MS specialist nurse? (Please select all that apply)
- By telephone
- By email
- The nurse visiting your home
- At an outreach clinic in a community setting
- At a specialist clinic in a hospital setting
<table>
<thead>
<tr>
<th>Experiences of people using MS specialist nurse services</th>
</tr>
</thead>
<tbody>
<tr>
<td>✮ 3. In the last 12 months, what has been the most common way you have received support from your MS specialist nurse? (Please select only one)</td>
</tr>
<tr>
<td>☐ By telephone</td>
</tr>
<tr>
<td>☐ By email</td>
</tr>
<tr>
<td>☐ The nurse visiting your home</td>
</tr>
<tr>
<td>☐ At an outreach clinic in a community setting</td>
</tr>
<tr>
<td>☐ At a specialist clinic in a hospital setting</td>
</tr>
</tbody>
</table>

| ✮ 4. In the last 12 months, outside of prearranged appointments, have you contacted your MS specialist nurse specifically to: (Please select all that apply) |
| ☐ Discuss possible treatment options |
| ☐ Discuss your medication |
| ☐ Discuss a relapse, new/worsening symptom or a sudden change in health |
| ☐ Get some general information about MS |
| ☐ Receive emotional support |
| ☐ I have not needed to contact my MS specialist nurse outside of prearranged appointments |

<table>
<thead>
<tr>
<th>5. Getting information</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the following section we would like to find out about your experiences of the MS specialist nurse service, specifically as it relates to getting the right information.</td>
</tr>
<tr>
<td>Using the options provided, please indicate how closely the following statements reflect your experience.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>✮ 1. My MS specialist nurse helps me when:</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want to know about different treatments available</td>
</tr>
<tr>
<td>I have questions about my current medication</td>
</tr>
<tr>
<td>I have questions about my symptoms</td>
</tr>
<tr>
<td>I want to discuss my care options</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. Your care</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the following section we would like to find out about your experiences of the MS</td>
</tr>
</tbody>
</table>
Experiences of people using MS specialist nurse services

specialist nurse service, specifically as it relates to your overall care.

Using the options provided, please indicate how closely the following statements reflect your experience.

**1. My MS specialist nurse:**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Always</th>
<th>Often</th>
<th>Occasionally</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is my first point of contact if I have any questions about my MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Involves me in decision making related to my own care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps me to make informed decisions about my care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides support and advice to my family and carers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refers me to other professionals when needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advises me on different care and support services available</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps me to access different care and support services available</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can adjust my care around any changes in my MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps me to take my medication correctly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

7. Independence and self-management

In the following section we would like to find out about your experiences of the MS specialist nurse service, specifically as it relates to self-management and maintaining independence.

Using the options provided, please indicate how closely the following statements reflect your experience.

**1. The support I receive from my MS specialist nurse:**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Always</th>
<th>Often</th>
<th>Occasionally</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helps me to be as independent as I can be</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps me to remain as active as I can be</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps me to take care of myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps me to understand my MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps me to maintain my quality of life</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps me to plan my care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps me to manage an oncoming relapse or a new/worsening symptom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Experiences of people using MS specialist nurse services

## 8. Access and availability

In the following section we would like to find out about your experiences of the MS specialist nurse service, specifically as it relates to the availability and accessing the service.

1. Using the options provided, please indicate how closely the following statements reflect your experience.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Always</th>
<th>Often</th>
<th>Occasionally</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is easy to contact my MS specialist nurse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can see my MS specialist nurse when I need to</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel comfortable contacting my MS specialist nurse, even for small problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel my MS specialist nurse is never too busy to help me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## 9. Additional comments

1. If you would like to tell us anything else about your experiences related to your MS specialist nurse and the service you receive, please use the box below.

## 10. Thank you

Thank you for your interest in this survey. Unfortunately people who do not currently have access to an MS specialist nurse or who do not have MS are excluded from this survey.
Experiences of people using MS specialist nurse services

11. Thank you

Thank you for your interest in this survey. Unfortunately people who are under the age of 16 are excluded from this survey.

12. Thank you

Thank you once again for taking the time to complete this survey.