Appendix G – patient/carer organisation statement template

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Alemtuzumab for the treatment of relapsing-remitting multiple sclerosis

Thank you for agreeing to give us your views on the technology and the way it should be used in the NHS.

Patients and patient advocates can provide a unique perspective on the technology, which is not typically available from the published literature.

To help you give your views, we have provided a template. The questions are there as prompts to guide you. You do not have to answer every question. Please do not exceed the 8-page limit.

About you

Your name: [redacted]

Name of your organisation: MS Society

Are you (tick all that apply): [redacted]

About MS

Multiple sclerosis (MS) is one of the most common disabling neurological conditions affecting young adults. Around 100,000 people in the UK have MS. For most people, MS is characterised by relapses followed by periods of remission, while for a minority it follows a progressive pattern from onset. However, even those with relapsing-remitting MS typically experience increasing disability and morbidity with entry into the secondary progressive phase. Genetic risk is well established with >57 genes now identified that drive the primary inflammatory response; and environmental triggers are also indirectly implicated. Although much progress has been made in identifying disease modifying treatments, these are not curative and even the most effective carry significant risks for treated patients. The progressive phase of MS remains refractory to treatment and this represents the main unmet need for affected individuals with this variable, unpredictable but threatening disease.

About the MS Society

The MS Society is the UK's largest charity for people living with MS, with approximately 38,000 members and 300 branches. The MS Society is the UK's largest charitable funder of research into MS. Since 1953 the MS Society has been providing information and support, fighting for change and in 1956 funded our first research project. We provide grants to individuals, for example in order to make home adaptations. We are committed to bringing high quality standards of health and social care within reach of everyone affected by MS

This submission has been prepared by the MS Society's Policy and Research directorate and is informed by:

- the results of an online survey - over 1000 people affected by MS told us about their views and experiences in relation to MS disease modifying drugs (DMDs) and relapses;
- a semi structured interview with an expert patient who has direct experience of taking alemtuzumab;
- secondary research into the costs of MS, and;

- clinical trial data from the CARE-MS I and CARE-MS-II, involving 563 and 628 people with relapsing remitting MS respectively, and a five year follow up study of the phase II CAMMS233 trial involving 198 people.

The following four appendices are attached to this submission:

- **Appendix A:** Transcript of interview with a patient expert
- **Appendix B:** A report on the perspectives of people with MS on relapses and disease modifying drugs.
- **Appendix C:** Free text responses to an open question on experiences of relapses and/or disease modifying drugs;
- **Appendix D:** Interview questions sent to the patient expert in advance of the interview.

Executive Summary

The clinical trial results show that alemtuzumab is highly effective at reducing relapses - appearing to be superior, in terms of relapse reduction, to a standard first line therapy; and highly effective at reducing disability progression. Alemtuzumab therefore has the potential to improve clinical outcomes and quality of life for a significant number of people with MS and to save the NHS and personal social services money.

Reduction in risk of confirmed progression of disability

The two year CARE MS II trial demonstrated that alemtuzumab significantly reduced the sustained accumulation of disability progression by 42 per cent compared with interferon beta 1a in patients who have relapsed despite first line treatment. During the trial 20 per cent of those on interferon beta 1a experienced worsening disability compared to 13 per cent of those taking alemtuzumab.

A five year follow up of study of patients on the Phase II CAMMS223 clinical trial have shown that alemtuzumab can have an impact on disability progression for up to five years – lowering the risk of sustained accumulation of disability by 72 per cent.

The potential to maintain function and have a greater quality of life are critically important, especially for a potentially debilitating condition such as MS that may move from the relapsing-remitting to the secondary progressive phase and for those who have a high risk of accumulating disability.

Reducing relapses

Relapses have a physical and sometimes debilitating impact on people with MS; the majority of people with MS felt relapses left them unable to do the things they wanted to do (95 per cent), slowing them down (98 per cent). As a result, 90 per cent of people with MS told us that they cannot be as independent as they want to be, with 58 per cent always or often relying on others for support.

Alemtuzumab has been shown in both the CARE MS I and CARE MS II to have a greater clinical effect on the rate of relapse than current first line DMTs, which reduce relapses by approximately 30 percent:

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In the Phase III CARE MS I trial those taking alemtuzumab were around 55% less likely to experience a relapse over the course of two years (40% people taking interferon beta 1a experienced a relapse compared with 22% taking alemtuzumab).

The results of the Phase III CARE MS II trial demonstrated that those taking alemtuzumab were around 50% less likely to experience a relapse over the course of two years (51% of people taking interferon beta 1a experienced a relapse compared with 35% taking alemtuzumab).

The five year follow-up study found that alemtuzumab reduced the rate of relapse by 69 per cent compared to interferon beta 1a.

Key concluding messages

The impact of the degree by which alemtuzumab has been shown to reduce relapse rate and disability progression should not be undervalued given the devastating effect that relapses and disability progression can have on an individual's quality of life. Approving alemtuzumab would increase the treatment options that people with MS have, which would maximise the possibility that people find a treatment that works for them, both in terms of efficacy and tolerance to adverse effects.

If alemtuzumab was not made available on the NHS, it would have the following implications for people affected by MS:

- Fewer people will receive treatment that works for them – many may not be treated at all, with an obvious impact on health outcomes.

- Even those receiving current disease modifying treatments will experience more relapses, worsening disability and a loss of quality of life than if they were able to take alemtuzumab.

- Fewer people with MS will be able to continue in full time employment. This means they would be less productive, and would need to rely on the welfare system sooner;

- People with MS would be more reliant on a carer and therefore less independent. People with MS would not be able to do the things they wanted to do and would feel physically limited by their condition as their MS progressed faster; carers will also experience poorer health and a loss of quality of life.

- Care and support costs met by the NHS and personal social services will be higher. The more people experience relapses and the resulting disability associated with it, the more people with MS will increase their reliance on NHS and social care services.

- People with MS will experience poorer mental well being. Currently two thirds of people with MS experience anxiety and/or depression. Anxiety is more common for relapsing MS and depression is more common for progressive MS.

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What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition?

1. Advantages
(a) Please list the specific aspect(s) of the condition that you expect the technology to help with. For each aspect you list please describe, if possible, what difference you expect the technology to make.

Alemtuzumab is a significant development in the treatment of relapsing-remitting multiple sclerosis (RRMS). In addition to significantly reducing annualised relapse rates it has also been shown to reduce the risk of disability progression for those with relapsing MS in comparison to interferon beta 1a, which has shown to be sustained over a five year period. Current disease modifying treatments (DMTs) available for RRMS are administered through monthly infusion, highly frequent and ongoing sub-cutaneous or intramuscular injections, or (for a small number of people) a daily oral treatment. Alemtuzumab comprises of one course (a daily infusion for five days) followed by a second course 12 months later (a daily infusion for three days), and in a declining number of cases a third or fourth course (same as the 2nd) after a further 12 months or more. We already see alemtuzumab having a considerable impact on health outcomes and quality of life for many of the people who have been able to take it with consequent benefits to the health care system and the taxpayer. Alemtuzumab has the potential to offer a vital additional option for people with MS and an important alternative to current DMTs for RRMS.

Alemtuzumab has undergone two phase III clinical trials – CARE MS I and CARE MS II. These trials, which involved 1191people with MS globally, aimed to investigate the effect of alemtuzumab on:

- annualised relapse rate
- time to six month sustained accumulation of disability
- various surrogate MRI brain scan indicators of tissue damage associated with MS

A further five year follow-up study of those on the phase II CAMMS223 trial, involving 198 people with MS, investigated the long-term safety and efficacy of alemtuzumab compared to interferon beta 1a in early active RRMS. The study provided evidence on the long-term effect of alemtuzumab on relapse rate and accumulation of disability.

The trials found that those taking alemtuzumab experienced the following benefits in comparison to interferon beta 1a:

1. A lower annualised rate of relapse
A relapse is defined as an episode of neurological symptoms, which lasts for at least 24 hours and occurs at least 30 days after the onset of any previous episode. In relapses, symptoms usually come on over a short period of time but often remain for a number of weeks – usually three to four - and can sometimes last for months. People with MS can experience a wide-range of distressing and debilitating symptoms from fatigue to visual impairment, mobility problems to cognitive problems. Relapses can vary from mild to severe. At their worst, acute relapses may need hospital treatment, but many relapses are managed at home, with the support of a

GP, MS specialist nurse, and other healthcare professionals. Although some people recover from relapses and experience complete remission, around half of all relapses leave residual problems; another important reason to reduce the frequency and severity of relapses.

Due to the varied and unpredictable nature of MS, determining an 'average' relapse rate is not straight forward; considering the number of people currently on disease modifying drugs it is estimated that a significant proportion of individuals with relapsing remitting MS experience one or more relapses per year.

Alemtuzumab has been shown in both the CARE MS I and CARE MS II to have a greater clinical effect on the rate of relapse than current first line DMTs, which reduce relapses by approximately 30 percent:

The two year randomised controlled CARE MS I study investigated the efficacy and safety of first line alemtuzumab compared with interferon beta 1a. The results demonstrated that alemtuzumab significantly reduced relapses by 54.9 per cent compared with interferon beta 1a. During the course of the trial 40 per cent of people taking interferon beta 1a experienced relapses compared to 22 per cent of people taking alemtuzumab. Further analysis of the data showed that 78 per cent of those on alemtuzumab were relapse free at two years compared to 59 per cent of those on interferon beta 1a.

The two year randomised controlled CARE MS II study investigated the efficacy and safety of alemtuzumab compared to interferon beta 1a in individuals who had relapsed despite first line treatment. The results demonstrated that annualised relapse rates were significantly reduced by 49.4 per cent. During the course of the trial 51 per cent of people on interferon beta 1a experienced relapses compared to 35 per cent of people taking alemtuzumab. Further analysis of that data showed that at two years 65 per cent of those taking alemtuzumab were relapse free compared to 47 per cent of those taking interferon beta 1a.

The five year follow-up study found that alemtuzumab reduced the rate of relapse by 69 per cent compared to interferon beta 1a.

2. Reduction in risk of confirmed progression of disability

The majority of people with MS experience a progression of disability over the course of the condition. It is estimated that approximately 65 per cent of people with relapsing remitting MS will eventually go on to develop secondary progressive MS 15 years after being diagnosed and 10-15 per cent are affected by primary progressive MS. Progressive forms of MS are characterised by a sustained accumulation of disability independent of relapses. This progression occurs at varying rates and can lead to a worsening of symptoms resulting in a permanent loss of mobility and the need to use a wheelchair, cognitive damage and permanent sight loss. There is also a real risk of accumulating disability for those with RRMS who are refractory to first line treatment.

The MS Society knows that addressing disability progression is a major issue for people with MS and currently represents an unmet treatment need. Our new

Research Strategy (2013-17) highlights research into progression as a major priority for the MS Society going forward. The strategy was formed in consultation with people affected by MS and the MS research community. It was approved by our Board of Trustees - the majority of whom are people affected by MS, either directly or as carers. It should be noted that many years ago, in the 1990s, the MS Society funded an early clinical trial into the use of alemtuzumab as a potential treatment for MS. We do not though have any financial stake in the product.

As well as greatly reducing the incidence of relapses, alemtuzumab appears to reduce the risk of disability progression, and therefore has the potential to increase quality of life over the medium to long term, for a significant number of people with MS who still experience relapses.

The CARE MS II trial demonstrated that alemtuzumab significantly reduced the sustained accumulation of disability progression by 42 per cent for those with first line treatment refractory RRMS in comparison to interferon beta 1a. During the trial 20 per cent of those on interferon beta 1a experienced worsening disability compared to 13 per cent of those taking alemtuzumab.

Clinical trials into alemtuzumab have shown that it can have an impact on disability progression for up to five years (five year CAMMS223 follow-up trial) – lowering the risk of sustained accumulation of disability by 72 per cent. We know from our consultation that this is an important aspect that people with MS would like treatments to address.

The rate of sustained disability accumulation did not differ between those on alemtuzumab and those taking interferon beta 1a in the CARE MS I trial.

Proving a benefit in terms of disability progression is notoriously difficult; but without at all minimising the difficulty of living with relapses, a product that has shown significant benefit here would be greatly valued by people affected by MS. The potential to maintain function and have a greater quality of life is of critical importance, especially for a chronic, long-term and potentially debilitating condition such as MS that so often evolves from relapsing-remitting MS to the secondary progressive phase.

(b) Please list any short-term and/or long-term benefits that patients expect to gain from using the technology. These might include the effect of the technology on:
- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (lifestyle, work, social functioning etc.)
- other quality of life issues not listed above
- other people (for example family, friends, employers)
- other issues not listed above

Patients can expect to gain the following benefits from using alemtuzumab:

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Reduction in accumulation of disability
Many of those who are refractory to current first line treatment are advised to stay on the same course of treatment despite ongoing disease activity or are switched to another treatment with similar efficacy. It is not surprising then that the majority of people with relapsing forms of MS are not receiving disease modifying treatment at all. For these individuals there is a risk of both more relapses and accumulating disability if they are without effective treatment, which could have serious implications on their quality of life and their ability to remain active and independent members of society. Alemtuzumab has been shown to be highly effective as a first and second line therapy and has been shown to reduce the risk of sustained accumulation of disability, over a five year period.

Quality of life (lifestyle, activities of daily living, independence)
A drug which can significantly reduce the number of relapses and disability progression is likely to have a considerable positive impact on the quality of life of the individual. People with MS have told us that relapses have a physical, mental and sometimes debilitating impact, affecting their ability to do day-to-day activities and significantly reducing their quality of life. In our survey, 95 per cent had experience of relapses that left them unable to participate in routine activities of daily living, nearly 90 per cent said they could not fulfil their usual roles and responsibilities and a further 98 per cent of people felt that relapses slowed them down.

People with MS reported that they wanted to avoid and prevent relapses from occurring as they resulted in a loss of independence. Respondents described relapses as 'set backs.' As one person put it, "*I want to be normal again and not have to endure debilitating relapses several times a year which set me back so far and mean I have to rely on others to help me, when I just want to be able to do the things that everyone else takes for granted*" (quote 259, appendix C).

The inconvenience and "paraphernalia" required to inject, especially when on holiday was remarked upon by many of the respondents. One person explained that "*one airport official asked what I felt was unnecessarily intrusive questions*" (quote, 110, appendix C) Another explained that, "*it [injecting] does involve planning when going on holiday as a fridge is needed in hotter climates, airlines need to be notified and delivery company contacted*" (quote 158, appendix C). Another related the impact to business travel: "*work wise, business travel is more of a concern when I have to manage a three times a week injection schedule*" (quote 42, appendix C).

Physical Symptoms
Prior to alemtuzumab our patient expert experienced new symptoms on a weekly basis, "*In 10 months I must've had about 20 different symptoms. Most of them were sporadic."* As a result of alemtuzumab she has experienced a significant improvement in all her symptoms, including pain. She no longer suffers from tingles, muscle spasms and cramps and all her old symptoms have, "*more or less disappeared overnight*." Occasionally our patient expert still experiences old symptoms when she is working too hard but does not experience any new symptoms. Consequently our patient expert feels she is able live life normally.

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Mental health

Alemtuzumab's effectiveness at reducing relapse rates and disability progression could significantly improve the mental well-being of people with MS. The emotional and psychological impact of a relapse and increase in disability should not be underestimated. Approximately two thirds of people with MS suffer from depression and/or anxiety due to both the physical changes caused by MS and the strain of living with such physical uncertainty[1]. Suicide is also more common in people with MS than the general population.[2] Alongside this, many people with MS do not get the emotional support that they need, with only 51 per cent of those who needed emotional support able to get it. One respondent provided a useful insight into the emotional impact of a relapse and the resulting loss of independence and increased dependency on family: "*Relapses are not only worrying, painful and distressing at the time but can take a considerable amount of time to recover from. I have been left with residual problems from every relapse I have had and then the worry of if I have another, is the disease progressing quicker than I thought - that is always a worry at the back of my mind. I then worry about the impact on my husband and that he has to take time off work to help me. The concern that he will not cope if I become severely affected by another relapse is a genuine worry as he gets extremely frustrated with the whole MS scenario. As a very independent lady, this adds its own issues to my state of mind and the fact that I cannot be there as readily for my children and colleagues*" (quote 55, appendix C).

Helping people with MS to remain in work

In an MS Society survey we found that, at some point, a relapse had prevented 82 per cent of people with MS from carrying out their work duties (paid employment) and that a further 89 per cent were unable to fulfil their usual roles and responsibilities during a relapse. Over half of the respondents reported that a relapse often or always has an impact on their ability to carry out their work duties.

The impact of relapses on people's ability to work can be significant as the responses to our survey illustrate. *"Relapses make sustaining full time work so much more difficult as they make each day such an effort and I am exhausted, although I still manage to hold down a full time job*". Another commented that she "*had two relapses, one straight after the other. These relapses can be very debilitating and take away your independence. I work part time and when I have to have time off sick I feel I am letting people down. I am currently undertaking light duties as my mobility is not what it was. This greatly upsets me as I feel that due to MS, I am unable to do the job that I have enjoyed for many years*" (quote 291, appendix C).

The difficulty of holding on to a job during a relapse was commented on by many of the respondents who either took annual leave to help cope during a relapse, or needed to take months off work to recover. The next two examples illustrate both of these scenarios:

"*I was diagnosed in 2007 and have had three relapses since. I am a clerical assistant and when I have a relapse, I lose vision in my left eye (optic neuritis). I have pain in*

[1] A large scale study of anxiety and depression in people with MS: A survey via the web portal of the UK MS Register, Jones et al (2012)

[2] ibid

my arm, leg, back and chest. The first relapse caused me to be off work for 8 months. The second relapse caused me to be away from work for 4 months. The most recent relapse was – in the words of my doctor – nipped in the bud. The five day treatment of steroid infusion was a great benefit to me and I was only away from work for one week. I only work part time now as the fatigue forces this as when I am tired, I have more apparent cognitive issues at home and work. I also stumble on a daily basis as my balance is very poor" (quote 265, appendix C).

"*I work full time for the NHS as an occupational therapist. To do this properly, I have to lose all aspects of life – I can't clean my home, go out and sometimes can't even make myself a cup of tea as I am so exhausted. I try to limit the impact at work by taking annual leave instead of sick leave if I feel I am losing energy which means I spend a lot annual leave in bed recovering from work*" (quote 84, appendix C).

The survey findings support the argument that relapses make continuing in a permanent job a challenge for some people living with MS. For example, one commented "*I am lucky that I have an understanding employer who has agreed for me to work from home part of the week when I am having problems (mobility wise). This I have found very useful from a fatigue point of view as well as allowing me to continue to work*" (quote 388, appendix C).

Some people had a less than positive experience with their employers as a result of an accumulation of relapses: "*I have had four bad relapses in the last 14 months causing me to have to take 6 months off work in total. I have now been made redundant and wonder if it was because of the disability?*" (quote 161, appendix C)

It is evident that relapses and an increase in disability progression can and do have a significant impact on people's ability to work. Unemployment among people with MS is higher than in the general population. A report by the Work Foundation[3] found that up to 80 per cent of people with MS stop working within 15 years of the onset of the condition. It also found that up to 44 per cent of people with MS retire early due to their condition – a higher percentage than the European average (35 per cent) and that more than 75 per cent of people with MS report that the condition has impacted their employment and career opportunities. An MS Society survey (2013)[4] found that of those who are of working age only 25 per cent were employed compared to 75 per cent of the wider UK population. A drug which could reduce the frequency and severity of relapses enabling people to continue in a permanent job with fewer disruptions to their day to day life would not only improve people's productivity when at work, but would allow more people with MS to stay in work for longer. This would then cost the taxpayer less in terms of the number of people becoming reliant on the welfare system and improve quality of life for people with MS and their carers.

Positive impact on carers

People with MS also rely on support from family and/or friends to help them to manage the impact of having MS, to help them remain independent and lead a fuller life. This includes support with everyday tasks like washing and dressing and getting

[3] Ready to Work? Meeting the Employment and Career Aspirations of People with Multiple Sclerosis, The Work Foundation (2011)

[4] A lottery of treatment and care – MS services across the UK, MS Society (2013)

out and about. At times of relapses and as disability progresses the need for this support increases and the impact on carers can be greater. Our survey on the needs of people with MS found that out of the 10,530 people with MS who responded 71 per cent received care, support or assistance from a friend of family member. Thus the effect of MS does not only affect the life of the person with the condition but can also significantly impact on family members and/or friends. A treatment such as alemtuzumab that has been shown in clinical trials to reduce relapses by approximately 50-55 per cent and disability progression by 40 per cent would therefore reduce the burden on the patient and the carer and is also likely to reduce management costs associated with MS.

A loss of independence as a result of a relapse can make people with MS more dependent on others for help. In our survey, 90 per cent of people with MS felt they could not be as independent as they wanted to be, 91 per cent of people with MS said that they had to rely on other people for help during a relapse and a further 93 per cent felt they were a burden on their family at some point during a relapse.

72 per cent of people agreed that administering an injection by themselves was difficult. The inconvenience of having to rely on others to inject as they couldn't inject themselves was highlighted in the responses as a problem. One respondent commented: "*It has never got any easier to inject or to ask my husband to do it for me. Indeed it can cause friction between us because we both get anxious*" (quote, 42, appendix C).

Choice of treatment

Since 2002, people with MS have been able to inject MS disease modifying drugs (DMDs). In 2007, Tysabri (natalizumab) was approved for those with rapidly evolving severe relapsing-remitting MS. People with MS who are taking Tysabri need to attend hospital to receive regular infusions. In 2012 Gilenya (fingolimod), the first oral pill for MS, was approved by NICE - a second line treatment for people with highly active RRMS, which requires them to take a pill on a daily basis. We are greatly concerned that despite the availability of these treatments there are a significant number of people currently not on any DMDs. In a recent MS Society report[5] which surveyed 10,530 people with MS, we found that 60 per cent of people with relapsing forms of MS were not taking any of the seven disease modifying treatments currently available.

Alemtuzumab should increase the choice of treatments for people with relapsing forms of MS, potentially as a first line option as well as for people for whom current standard DMDs would not be appropriate due to treatment failure, side-effects or lack of tolerability.

It is clear from the results of our survey and from people's experiences, that relapses can be an unpleasant and debilitating feature of living with MS, with long lasting physical and psychological effects on not only people living with MS but their carers too. Any drug that is more effective than the current DMDs at reducing the risk of sustained accumulation of disability and reducing relapse rates has the potential to

[5] A lottery of treatment and care – MS services across the UK, MS Society (2013)

transform the lives of people living with MS and their ability to have a greater quality of life.

2.Disadvantages
Please list any problems with or concerns you have about the technology. Disadvantages might include:
- aspects of the condition that the technology cannot help with or might make worse
- difficulties in taking or using the technology
- side effects (please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- impact on others (for example family, friends, employers)
- financial impact on the patient and/or their family (for example cost of travel needed to access the technology, or the cost of paying a carer)

The adverse events associated with alemtuzumab, which were identified during the clinical trials, particularly during the administration of this treatment included: infusion reactions, infections, thyroid disorders and immune thrombocytopenia or ITP (an autoimmune condition associated with a lowered platelet count) - regular blood tests are required to monitor this. Three patients on alemtuzumab developed cancer of the thyroid which was also treated. There was one fatality caused by ITP in a previous phase 2 clinical trial of alemtuzumab. Investigators subsequently changed monitoring procedures to screen for this unexpected side effect, and have not had a fatality associated with ITP since. Although there are a number of treatable side-effects some which, while uncommon or even rare, are serious. ITP is serious but treatable; more rarely, Goodpasture's syndrome is far more difficult to treat. A further disadvantage identified by the patient expert interviewed by the MS Society is that although the treatment itself is only administered once a year, these potential side effects mandate regular blood tests, even well beyond the treatment period.

3. Are there differences in opinion between patients about the usefulness or otherwise of this technology? If so, please describe them.

The MS Society is not aware of any differences in opinions between patients about the usefulness of alemtuzumab.

4. Are there any groups of patients who might benefit **more** from the technology than others? Are there any groups of patients who might benefit **less** from the technology than others?

The MS Society expects this technology to benefit people with relapsing-remitting MS. We do not know of any subgroups of people with relapsing-remitting MS who would benefit more or less from the technology.

Comparing the technology with alternative available treatments or technologies
NICE is interested in your views on how the technology compares with existing treatments for this condition in the UK.

(i) Please list any current standard practice (alternatives if any) used in the UK.

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The MS Society is aware of the following current disease modifying drugs used to treat relapsing remitting MS as standard practice: Avonex, Rebif, Betaferon, Extavia, Copaxone, Tysabri and Gilenya.

(ii) If you think that the new technology has any **advantages** for patients over other current standard practice, please describe them. Advantages might include:
- improvement of the condition overall
- improvement in certain aspects of the condition
- ease of use (for example tablets rather than injection)
- where the technology has to be used (for example at home rather than in hospital)
- side effects (please describe nature and number of problems, frequency, duration, severity etc)

The advantages of alemtuzumab over other first line licensed treatments for MS (Avonex, Rebif, Betaferon, Extavia, Copaxone and Tysabri) can be categorised as follows:

- Effective at reducing disability progression: On the CARE MS II trial, people with MS were around 42 per cent less likely to experience disability progression over the course of two years. Over five years, alemtuzumab has been shown to lower the risk of sustained disability by 72 per cent.

- More effective at reducing relapses than current first line treatments for RRMS: On the trials, people with MS were between 50 and 55 per cent less likely to experience a relapse in comparison to interferon beta 1a over a two year period. This clinical effect is greater than for current first line DMDs, which generally reduce relapses by approximately 33 per cent.

- Improved treatment adherence: Due to the mode and frequency of administration of alemtuzumab issues such as treatment adherence and compliance associated with the current standard DMTs will be less of a problem.

- Improved lifestyle and quality of life: The possibility of having an MS drug administered only twice via infusion with the possibility of a third course of treatment will potentially significantly increase the quality of life of individuals with MS. People with MS would be more independent as they would not need to rely on others to help them to inject. They would also have fewer relapses and would therefore experience fewer disruptions to their working life, enabling them to stay in employment for longer. There would be no long-lasting social visibility of treatment as only two and possibly three infusions are required. It would also give people with MS greater freedom particularly when travelling. Current treatments need to be refrigerated and require administrative preparation when travelling abroad.

- Less dependent on carer: A treatment such as alemtuzumab that has been shown in clinical trials to reduce relapses by approximately 50-55 per cent and disability progression by 40 per cent would therefore reduce the burden of care and support on the carer as well as the patient.

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The personal experience of people with MS who have tried current first line treatments for RRMS and the impact it has had on their lives are discussed below. These findings are taken from our survey on the perspectives of people with MS on relapses and disease modifying drugs.

1. Injection site reactions as a result of highly frequent injections

Skin indentation and a growing inability to cope with regularly injecting were a common theme amongst respondents, including an increase in difficulty when injecting over long periods. One person stated: "*It is getting more and more uncomfortable to inject as the original sites around my body are now dented inwards and are now unsuitable for injection. I have contacted my MS nurse who has given me ideas on suitable places to inject…the sore injection sites rub on my clothes during the day*" (quote 239, appendix C).

Most people who completed the survey found regularly injecting an unpleasant experience; 87 per cent of people with MS on DMDs at some point felt uncomfortable injecting with over 55 per cent of people finding it always or often uncomfortable to inject. A complaint among some respondents was the effect of scar tissue and fat atrophy, including injection site ulcers. Others complained that constantly injecting was not sustainable: "*injections are not a long term solution – there are only so many sites a body can put up with...*" (quote155, appendix C).

In some cases, complications with injection sites have resulted in emergency admissions. "*One experience I had about two years ago involved an injection site becoming infected causing a cyst on my stomach. When the pain became excruciating I ended up in A&E at 2am having it lanced under local anaesthetic. This resulted in me having weeks off work (unpaid), a district nurse having to visit every day to dress the wound and I believe the incident triggered a relapse which has since left me unable to use my right hand to write with ever since.*" (quote, 283, appendix C).

2. Pain and stress associated with regular injections

Respondents pointed to a relationship between the length of time spent injecting and a heightened sense of anxiety. As one respondent put it: "*the stress and anxiety caused by injections has almost as much effect on my quality of life as the MS condition itself*" (quote, 267), another described it as a "*three-weekly dread*" (quote 26, appendix C). Some respondents described how they had tried to deal with the anxiety of injecting, which they claimed had caused them to develop a 'needle phobia.'

A common theme amongst respondents was a perception that their MS symptoms exacerbated difficulties associated with injecting. One explained how "*the injections are difficult with the numbness in my fingers and hands*" (quote 311, appendix C). Similarly, another described the difficulty of injecting without a steady hand: "*it [injecting] begins to control your life…it is against human nature to hurt yourself and even more tricky when trying to inject with a tremor*" (quote 53, appendix C

Respondents described how injecting during a relapse made them feel worse about living with their MS: "*I initially thought when I started injecting I would not have so*

many relapses but in reality, I still get them although I tell myself that I get less now. I hate injecting through a relapse because of the effort and the feeling of they are not working so why bother putting myself through the trauma. I have not missed an injection but it is more my wilful nature than what I want to do" (quote 73, appendix C).

(iii) If you think that the new technology has any **disadvantages** for patients compared with current standard practice, please describe them. Disadvantages might include:
- worsening of the condition overall
- worsening of specific aspects of the condition
- difficulty in use (for example injection rather than tablets)
- where the technology has to be used (for example in hospital rather than at home)
- side effects (for example nature or number of problems, how often, for how long, how severe).

The disadvantages of the technology compared to current treatments include:

- Side-effects: The clinical trials demonstrated that side-effects such as infections and thyroid disorders were more common in those taking alemtuzumab than those receiving interferon beta 1a. Alemtuzumab is also associated with more serious side-effects, for example, ITP. However these are uncommon and in most cases treatable. Our patient expert H reported that the side effects were at their most intense whilst she was in hospital. However H says she felt fine within two to three months of being discharged. The potential side-effects of alemtuzumab and the risk of developing other autoimmune conditions was a concern for H but "*having gone through a year of really aggressive MS, none of the side-effects sounded worse than what I had already gone through…The risks were significant but set against the idea that this wasn't a condition that was going to go away. I was still having symptoms. I was still being reminded on a daily basis that I had MS. I thought…if it helps with the symptoms and if it means that this is as bad as it's ever going to get them I was willing to give it a go*" The side effects of taking alemtuzumab should be weighed against the advantages in terms of reducing relapses and delaying disability progression.

Research evidence on patient or carer views of the technology
If you are familiar with the evidence base for the technology, please comment on whether patients' experience of using the technology as part of their routine NHS care reflects that observed under clinical trial conditions.

The MS Society conducted a semi structured interview with an individual who had experience of taking alemtuzumab. The interview has been transcribed and anonymised. The transcripts of the interview can be read in full in appendix A and a copy of the interview questions is included in appendix D. The personal experience of a person with MS who has taken alemtuzumab and the impact it has had on their and their partner's life is discussed below. In addition to this interview, we have regular contact with other people who have and are taking alemtuzumab.

Course and/or outcome of the condition

H did not expect alemtuzumab to do anything else beyond freezing the condition where it was at: "*I wanted to make sure that my condition got no worse and potentially slightly better… I was thinking of the long-term – this was the first time that any treatment I had ever been offered that had the potential long-term benefits as well as immediate benefits…If we can stop it at this point, we know we can cope with it…but if my condition continued to progress at the rate and the way it had following diagnosis then it would've been untenable. I don't know what the end-point would've been but it wouldn't have been a good place*."

"*It felt like alemtuzumab was giving me my life back. It was giving me a chance of having the life I had prior to diagnosis and without alemtuzumab I wasn't certain about what my life would've ended up being…Saying yes to alemtuzumab was less terrifying than living with MS untreated for the rest of my life…I could see a point where it would become untenable to live with and I didn't want to get to that point*."

Quality of life (lifestyle, work, social functioning etc)

Prior to MS, H reports life before MS as being "*relatively normal, happy and fulfilled life*." She and her partner both worked full time and "*used every opportunity to experience life and have fun*." However, when H was first diagnosed with MS, "*It stopped my life, absolutely dead stop…the accumulation of symptoms and the fatigue had already started having an impact on how we were living our lives about 18 months before the diagnosis…We didn't go out. We didn't enjoy ourselves. It was horrific. It was like living through months and months of hell*." As well as her social life coming to an end H also had to take two months off work after diagnosis and then resigned a few months later as she just couldn't continue working. H says she is now "normal" and for her MS has become "*a minor irritation that I have to take into account occasionally.*" She says: "*It [alemtuzumab] gives me control of my life. I work full-time. I never thought at the time of diagnosis that I would be working…It has given me my life back*." Her partner also noted that he couldn't "*remember the last time I needed to get concerned…It's brought our life back to as it was before diagnosis…We don't feel like our lives are constrained anymore…It really does just feel like a normal life*."

Physical symptoms

Prior to alemtuzumab H's MS was quite active with new symptoms cropping up on a weekly basis, "*In 10 months I must've had about 20 different symptoms. Most of them were sporadic."* As a result of alemtuzumab H has experienced a significant improvement in symptoms. She no longer suffers from tingles, muscle spasms and cramps and all her old symptoms have, "*more or less disappeared overnight*." H says she still does experience some symptoms, although no new symptoms, but they are manageable and she sees them more as warning signs that she is over-doing it: "*If I'm experiencing symptoms I know I need to have time off. It's [alemtuzumab] given me more control of my MS*." This improvement was not expected by either H or her partner or the medical team – the effectiveness of the treatment came as a surprise.

Mental health and well-being

When H was diagnosed no support was offered nor any information on MS. This led to H and her partner feeling very isolated and alone as they were left to cope with the diagnosis on their own. H became depressed, increasingly withdrawn, as the

awareness of what the implications of the diagnosis could be set in and was in a state of denial regarding her diagnosis. Consequently she was cut off from family and friends, which meant the "*burden of support fell squarely on Adrian's shoulders*." H said, "*I probably wouldn't be here, alive, if he hadn't been with me*."

The diagnosis of MS also had an impact on H's partner: "*I struggled…I think I was certainly suffering from a degree of stress, which resulted in physical symptoms. I started to feel unwell and I wasn't able to sleep. We were heading downhill physically and for me, as a result of the stress of the situation and the unknowns – not having the support and because Helen was very withdrawn. We both ended up very isolated and feeling that really it was the two of us in the world*." H's partner also had to take a lot of time off work to care for H.

Views on current first line treatments

H was not offered any disease modifying treatment for her MS when diagnosed and fell into a state of depression and denial. Once H began to come to terms with her condition she began to consider her treatment options and realised beta interferon was her only option. She questioned whether beta interferon would fit into their lives, given she would need to inject several times a week. For them, "*beta interferon didn't seem to be that effective…and the side-effects of beta interferon seemed to be as bad as the some of the symptoms H was suffering. It seemed very marginal as to whether there would be any benefit to beta interferon*." H found the side-effects "*horrifically off-putting. It seemed the treatment was worse than the condition."* She also said it was a "*daily or once a week reminder that you're a sick person*." On this basis H refused to take current first line treatments. She also declined to participate in an earlier comparison clinical trial on alemtuzumab as there was a possibility that she would be randomly allocated to the interferon beta 1a group.

H believes that the choice of treatments for those newly diagnosed is limited and offers no hope. For those who are newly diagnosed H says there is "*so much isolation, so much despair about whether it is normal, whether it is going to continue*" and that "*alemtuzumab and the new drugs that are coming out really are a glimmer of hope of people being able to see beyond that treatment to a life where their condition will be manageable. I think putting people even slightly more control in of their condition is so important because they are going to be living with it until they die."* MS "*takes over people's lives and becomes all that they are and I think alemtuzumab gives people a chance to be somebody who just happens to have MS rather than being MS themselves."*

Are there any adverse effects that were not apparent in the clinical trials but have come to light since, during routine NHS care?

The MS Society is not aware of any adverse effects that were not apparent in the clinical trials.

Are you aware of any research carried out on patient or carer views of the condition or existing treatments that is relevant to an appraisal of this technology? If yes, please provide references to the relevant studies.

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Alemtuzumab for the treatment of relapsing-remitting multiple sclerosis

Perspectives of people with MS on relapses and disease modifying drugs. MS Society, April 2010

Availability of this technology to patients in the NHS
What key differences, if any, would it make to patients and/or carers if this technology was made available on the NHS?

1. People with MS would experience fewer relapses and a reduction in disability progression compared to standard first line disease modifying therapy. This would have the following impact on patients and/or carers:

- Enable people with MS to stay in employment for longer with fewer disruptions. People with MS could then contribute to the economy for longer, reducing the need for people to depend on the welfare system;

- Lower the costs to the NHS and personal social services as more people with MS will experience fewer relapses and a reduction in disability progression. This would reduce the need to rely on these services as much whilst also limiting the number of emergency admissions and appointments to see healthcare professionals either because of injection site complications;

- People with MS would be less anxious about experiencing another relapse. This would improve their mental and physical health more generally, giving people with MS the confidence to lead a full life and a better quality of life;

- People with MS would be less reliant on a carer and be more independent. People with MS would stand a better chance of being able to do the things they want to do, rather than feeling physically limited by their condition

2. Alemtuzumab would give people with MS and their carers an improved quality of life. This would have the following impact on patients and/or carers:

- Fewer relapses and reduced disability progression would reduce the burden of care and support on the carer as well as the patient.

- People with MS would have more choice about the treatments they take - weighing up efficacy, side effects and convenience. Alemtuzumab offers an alternative treatment choice for people with relapsing MS

What implications would it have for patients and/or carers if the technology was **not** made available to patients on the NHS?

If alemtuzumab was not made available on the NHS, it would have the following implications for people affected by MS:

1. People living with MS would experience more relapses and an increase in disability progression compared to those receiving standard disease modifying treatments. This would have the following impact on patients and/or carers:

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal (STA)

Alemtuzumab for the treatment of relapsing-remitting multiple sclerosis

- Even those receiving current disease modifying treatments will experience more relapses, worsening disability and a loss of quality of life than if they were able to take alemtuzumab, including loss of mobility and eyesight, pain, fatigue and cognitive impairment;

- Fewer people with MS will be able to continue in full time employment. This means they would be less productive, and would need to rely on the welfare system sooner;

- People with MS would be more reliant on a carer and therefore less independent. People with MS would not be able to do the things they wanted to do and would feel physically limited by their condition as their MS progressed faster;

- Increase the costs to the NHS and personal social services. The more people experience relapses and the resulting disability associated with it, the more people with MS will increase their reliance on NHS and social care services.

- People with MS would be increasingly anxious and depressed about relapses and the disability associated with them.

2. Without an alternative, people with MS will be limited in choice to existing treatments:

- Fewer people will receive treatment that works for them – many may not be treated at all, with an obvious impact on health outcomes.

- Treatment options will continue to involve significant planning and disruption to every day life.

- Significant numbers of people with MS will continue to stay dependent on others

It is vital that, with an increasing number of alternatives entering the market for the treatment of relapsing remitting MS, people with MS have access to the right drug for them at the right time and there should be a focus on the potential to maximise quality of life for the individual.

Are there groups of patients that have difficulties using the technology?
The MS Society is aware of the following groups of patients who should not be using the technology:
- Those who are pregnant
- Patients who have cancer
- Patients who have had chemotherapy for cancer
- Patients with progressive MS, without relapses

Equality
NICE is committed to promoting equality of opportunity, eliminating unlawful discrimination and fostering good relations between people with particular protected characteristics and others. Please let us know if you think that this appraisal:

- could exclude from full consideration any people protected by the equality legislation who fall within the patient population for which [the treatment(s)] is/are/will be licensed;
- could lead to recommendations that have a different impact on people protected by the equality legislation than on the wider population, e.g. by making it more difficult in practice for a specific group to access the technology;
- could lead to recommendations that have any adverse impact on people with a particular disability or disabilities.

Please tell us what evidence should be obtained to enable the Committee to identify and consider such impacts.

Other Issues

Please consider here any other issues you would like the Appraisal Committee to consider when appraising this technology.

Appendix A - Transcript of interview with a patient expert

H is a patient expert with experience of taking alemtuzumab. She had her first dose of alemtuzumab in 2005 and the second course in 2006

"H" and her partner "Ad" were interviewed by Asha Kaur, Policy and Campaigns Researcher, of the MS Society.

A: When were you diagnosed with MS?
H: The simplest answer to that is that it was the 9th August 2005, up in the Neurology clinic in Addersbrook Hospital in Cambridge.
A: How did your diagnosis for MS come about and how long did your diagnosis take?
H: It's strange I was looking at the dates for it last night. It felt like it took for ever but in actual fact it was a relatively short time between me first having symptoms that I thought were a little bit odd and needed to be investigated and actually being on the clinical trial. That period was about two years.
A: Two years?
H: So, it was very, very quick.
Ad: Yes. The right place at the right time, ultimately
H: Yes, we have been extremely lucky and that's been backed up by what I've heard about MS treatments locally in the UK, in Europe. We have been so lucky to just be in the right place at the right time. Umm, but it came about because I had a new job…I started a new job in September 2004. It wasn't a job that I particularly enjoyed. It was quite a stressful environment. I started getting some strange symptoms. My arm, the top of my arms and my shoulders felt hot. I mean they weren't hot to touch but there was a hot feeling there. Um, and I started feeling tired, um, that wasn't sort of cured by sleeping. I'd get really ratty. I started having extreme mood swings. Um and then I finally had a symptom that seemed really strange, which is when I bent my head forward my right thigh went numb and tingly and it was a bit of a novelty. It wasn't particularly scary at the time. It was like "look I can do this and my thigh goes numb!" but because of the stiff neck and the hot neck and the rest of it I decided in December to go to an Osteopath, um, and she did the crunching and all the rest of it. At the end of the consultation I mentioned, "by the way I've also got this really strange symptom you might be interested in: if I bend my head forward my thigh goes numb and tingly and she absolutely freaked out and started talking about "you must go and see your GP immediately. It could be a spike or a bone growing into your spinal cord, it could be a brain tumour, it could be this, it could be that. So, that was quite concerning and that was just before Christmas 2004. So I wasted no time and went to see my GP in February! And when I told my GP about this again she freaked out completely and started talking about, "we need to get you seen by specialists because any kind of symptoms like this are an issue" Um and my, that was quite a shock because, it was a GP who is no longer at our surgery who I had a fairly good relationship with and when she was concerned, it made me concerned and of course in the back of my mind that was bubbling away and I started getting more and more symptoms. My fingers on my right hand were getting numb and tingly; when I bent my head forward my feet were getting numb and tingly. I was suffering with insomnia and so and so forth.

A: So a range of symptoms then?
H: Yes
Ad: I was going to say, Helen, actually there was a period of about a year leading up to this point where Helen had noticed some symptoms and fairly minor ones and did actually go and see the doctor on at least one occasion. Ah and um, actually the two main symptoms. One was the tingly legs but the other one was a lot of problems with pain.
H: Oh yes. Pain running down the right side of my body
Ad: So there was a process of, well maybe it's gall stones, maybe it's this, maybe it's that and we went up to hospital several times for a whole range of…
H: That came after talking to Dr Kenny in February
Ad: Yes, the hospital appointment, but in the first instance they discovered, in terms of MS, was dismissed out of hand by another GP at the practice
A: So your GP and he said you would need to go see some specialists and then this other GP…
H: Just dismissed everything out of hand – it was all in my mind. I think being a woman in her 30s with a very traditional male GP close to retirement age, if you don't have a broken leg or something obvious it's either your hormones or all in your mind
Ad: So there was a period of not really being sure on the basis of one on one hand we were being told this could be really serious and you need to get it sorted out immediately etc etc and on the other hand one of our other GPs at the surgery saying "Oh, it's all fine you don't need to worry about anything. Go away and take two paracetamols." So there was a kinda conflict right at the beginning between the advice we were getting from two different GPs. Um but…
H: But having spoken to Dr Kenny I went away and then in April 2004, sorry no, April 2005, sorry. I started ending up having a lot of different…
A: that was about a year then from when you first saw your GP to...
H: Sorry, no. I saw my GP February 200…February 2005. Yes because it was the same year I got the diagnosis. In April 2005 I had my first appointment with the neurology clinic in Addersbrook and explained the symptoms and they started off with "Well, no idea what it might but we'll have to start doing some tests. So over the course of April and May I had a full blood work-up, I had an MRI scan, um and a lumbar puncture, which was fun. I have to say, I love medicine and I think what we can do medically is fantastic. Having the lumbar puncture was the first time that I've ever been terrified of going to a hospital. You came with me and it was fine. I mean, it was less painful then having an injection in your arm or a blood test taken but it was quite a…it felt like a very significant procedure, which again reinforced the idea that I was dealing with a significant range of symptoms rather then it just being in my mind,. So I had a couple of meetings with neurologists as all of these things were interspaced with an appointment here, a blood test there, a another appointment here and an MRI scan, so it was all interweaved. In July 2005 I had an appointment where I was diagnosed with pernicious anaemia and told you have a very frisky, technically what we can a frisky immune symptom. You have this pernicious anaemia. You'll have to taker B-12 tablets for the rest of your life. It's something people used to die of and it's also something that used to be in my family. I went away thinking well this solves everything. That explains all the symptoms. These

were all peripheral neuropathies. That's fine. I can cope with that diagnosis. It's scary. It's horrible but at least it's a diagnosis. We went away on holiday and I went back after holiday for what I thought was a catch-up appointment, walked into the office and sat down and the young registrar said, "yes, well we've got the pernicious anemia, we're okay with that but, guess what as a bonus you've also got MS!

A: So how soon was this after…?

H: It was about 2 weeks after I had the pernicious anaemia diagnosis and he seemed to think that was as far as his job went: was just telling me. He gave me some steroids, told me there were clinical trials in the hospital that I might be eligible for. That there was an MS nurse network that I might be put forward to be in contact with. Um but essentially that was it as far as he was concerned, he washed his hands off it all.

A: So you were offered no treatment?

H: No treatment was discussed, no support was discussed. I was just simply left. "Congratulations, on your way. Bye." I can just remember that moment. I don't remember leaving his office but I do remember sitting outside in the waiting room and all of those classic symptoms of shock and everything around me died away. There was a rushing noise in my ears and everything focussed on a single point and I was just…in tears and it felt like my life was over because all I knew about MS at that point was the advertising campaigns in the 80s and 90s with the girl with the ripped out spine and people in wheelchairs and…it was horrific and I came back to the college where you were working and we just sat outside and the implications began to sink in. Are we going to have to sell and buy a bungalow? Am I ever going to be work again? What does this mean? Am I going to be wheelchair bound in five years time? What happens now?

A: What was your life like before your diagnosis? Were you very active? Socially? Work-wise?

H: It was…yeah…it was relatively normal. We're not social people. We don't go out to the pub and meet with huge groups of friends but I mean we had a full working life, worked full-time. Had lots of friends that we used to meet for coffee or lunch or go out to the cinema with, live music. I mean we were…we don't have children and we don't have family living near us. At that point…we used every opportunity to experience life and have fun. It was great. We'd moved up from Cornwall where we had a very active social life, and a very active…walking around, going to the beach. So our life wasn't that active because we hadn't sort of adjusted to being in Cambridge. Apart from that it was a normal, happy, fulfilled…work life balance was good. Um at that point, everything stopped and I have to confess, from that point of diagnosis up until the very first time we met Alasdair I had a very patchy memory of what was going on because I think it was too much for me to process and that on top of the effect of the steroids. I don't react well to steroid treatment!

Ad: I think part of the problem was the fact that the…I suppose the year to the 18months leading up to the diagnosis, the accumulation of symptoms and the fatigue had already started to have quite an impact on how we were living our lives. So I think the impact started probably about 18months before the diagnosis.

H: But certainly after the diagnosis…

Ad: Once the diagnosis came we felt so alone and so isolated. Helen was saying we weren't offered anything at all. Um, in terms of …not even in terms of just information
H: No
Ad So, it's of course then…obviously, the internet is the first place you go to, the MS Society website and various others and started to get a feel for what this MS thing was. Again my only understanding of MS was the posters in the 80s of people in wheelchairs with the spine torn out. So my only real appreciation was that this was something that was going to be very serious and extremely debilitating and iit was all going to happen very quickly.
H: And with no end-point. I mean at least if I had a Cancer diagnosis you would've thought I have this issue but there's surgery, there's chemotherapy, there's radiotherapy, there are treatments, there may even be a cure! But with MS we were given no hope of any kind of any kind of alleviation of symptoms and certainly no hope of any kind of cure or return to normality. It was….we sat around and thought is this what it's going be like for the rest of a short and nasty life.
Ad: So there was a fair degree of depression set in and to be honest it really did affect both of us. Umm, but…I guess…we kind of plodded on and at some point, I can't remember how far…beyond diagnosis we were put in touch with the MS nurse.
H: It was about a couple of months after. We were sent an appointment through the post from our local hospital who had an MS nurse clinic. We went up and saw her and she was nice enough but she was nice enough but she was absolutely useless in terms of any kind of practical support. I think because I wasn't disabled enough to qualify for some types of support but then too newly diagnosis to be offered other kind of support.
Ad: And in some respects it didn't help either that when we went to see the MS nurse and there were two other people to see the MS nurse. One of them was barely mobile and the other was in a wheelchair. So we sat waiting to see the nurse thinking so this is what we've got to look forward to?

A: So how did your life change with your MS and what impact did it have?
H: It stopped my life, absolutely dead stop. I mean I had two months off work on a sick certificate and when I went back to work that environment had changed utterly because my boss didn't like woman to start off with but particularly now that I was a middle-aged woman who was sick. It became absolutely untenable. The relationship with my boss completely broke down to the extent that I actually resigned a few months later after getting back to work because I just couldn't continue working. So my job came to an end, our social life came to and end because nobody wants to socialise with people who are depressed and all they want to talk about is this new issue they have. We didn't go out, we didn't enjoy ourselves. It was...I mean I'm getting a bit choked up thinking about it. It was horrific. It was like living through months, and months and months of hell. It really was
Ad: In retrospect one of the slightly annoying things about that was, only half of that was down to the symptoms of MS the other half was down to the fact that we were just floundering around, not understanding what was happening
H: Not having any support
Ad: where we were going to go in the future

H: That uncertainty would feed into the back of my brain and with the depression that I was going through at the time as well…
Ad: that would exacerbate the MS symptoms
A: Did you get any support for the depression? Were you put in touch with a counsellor or any psychological support?
H: No, no. I did see the GO again about it. I saw two of the GPs – one was the old traditional male GP who said don't be daft you haven't got MS. There's nothing wrong with you. It's probably something silly like CJD, which was fantastic. The other one...that was one of the other problem – not even our allocated medical team, our GP surgery, really k new anything about MS either. The other doctor, the one who started off the whole diagnosis process, she did get me a few other appointments for the stabbing pain I was having down my side. She sent me to the local hospital for scans to see if it was gall stones or a tumour but again nothing physically was wrong with me, so again we put that down to the MS. Throughout all of that period I was getting new symptoms, just randomly cropping up, on a almost weekly basis.
A: So it was quite active?
H: It was massively active. I totted up a list of symptoms the other day and in 10 months I must've had about 20 different symptoms cropping up. Most of them were sporadic. They would crop up for a little bit and then disappear, so you almost begin to feel paranoid about your own body: did I really feel that or what was that? Have I just slept on my arm wrong or is it really numb and tingly.
Ad: No support at all in terms of the mental health
H: No, I was given anti-depressant tablets and that was pretty much it.
A: Presuming you (Adrian) were providing Helen with all the support?
Ad: Yes
H: I have to say, in terms of us been given support we weren't given any. There's a question further on here, what support did I need from friends and family? I was in a place where I was finding it really difficult to process the whole idea that I was in fierce denial. The only strong way that I could get myself through this was to deny any of this was happening. So I pretty much got cut off from friends and family because I didn't want their help. I don't need people's help. There's nothing wrong with. Everything is fine. I don't want any support from friends and family, which of course the burden of support for me as an individual fell squarely on Adrian's shoulder's The levels of support that I had from Adrian – I probably wouldn't be here alive if Adrian hadn't been with me.
As: How did that impact on you Adrian?
Ad: I wouldn't say that I…I wouldn't call it depression but certainly in terms of mental health, I struggled a bit and the stress of it. There was a feeling again of social isolation on the basis of…because Helen didn't want to socialise not even with family and the rest, I…I became fiercely protective of Helen. Every waking minute that I wasn't at work I was by Helen's side and overtime it does become very tiring. I think certainly suffering from a degree of stress and which ultimately resulted in physical symptoms for myself. I started to feel unwell and I wasn't able to sleep. So, we were heading downhill physically but largely, obviously, for me, as a result of the stress of the situation and the unknowns - not having the support and because Helen was very withdrawn, very insular. I guess, I just fell in that pattern of behaviour and so we

both ended up very isolated and feeling that really it was the two of us in the world and that was it.
H: I think that was one of the biggest problems we had at the time. In a sense I was more fortunate because I was the person with the condition, so if there was ever going to be any support I was going to be the one that the support would be targeted at. The support for carers of people and particularly support for carers of people who have had just had a diagnosis of anything. It's incredibly difficult to be the person in the background who's meant to pick up the pieces. I remember you saying that the only support you really had was, going onto, strangely enough the MS Society website and going to the Carer's Forum and actually reading through those and seeing what other people were experiencing and realising you weren't the only one who was being ignored.
Ad: I have to say the MS Society website was probably the most useful source of information and indirect support that I was able to find at the time. Fortunately I had a very understanding manager at the time as well. In those first few months I took a lot of time off work as well, which in retrospect I'm not sure if that was necessarily a good idea in that in some respect…
H: It reinforced isolation and feeding on each others…
Ad: It had taken me out of my normal routine as well and away from the social contact of the working environment

A: So when were you first introduced to Alemtuzumab?
H: Well, we had a phone call from Jackie who was the nurse associated with the A clinical trials, probably around September 2005. I spoke to her whilst I was at work and she chatted and said there were a couple of trials that I might be interested but they were there and they could help and that was the first time...I have to say, again I can remember isolated moments highlighted in my memory, I can remember that phone call with Jackie and those were pretty much her words: you're not alone, we're here, we have treatments, we can help. I just burst into tears and told her I was still suffering from understanding the situation and the implications and I couldn't think about adding another layer of complications on top of it, so it's very nice but not now.
Ad: There was also still I think at that time a fairly significant degree of denial
H: I think there probably was, yes.
Ad: Certainly from my perspective there seemed to be an element of: Well why would I be interested in any of that because I'm fine.
H: I'm not a sick person
Ad: despite the huge array of symptoms that Helen was acquiring on an almost daily basis it took a while. I found it very difficult. I found that a very difficult time period on the basis that…knowing that actually there were choices, and there were people we could talk to, there was support available. I didn't want to put pressure Helen in any kind of overt way given Helen's personality any kind of overt pressure is going to result in exactly the opposite! I felt for quite a while that I was walking a very fine line between trying to encourage Helen to open up about the condition and to go and talk to the team at the clinical trials and begin to start looking at Helen's and what our options were but at the same time not wanting to apply pressure

H: I mean one of the other things was, I think towards the end of 2005 we were beginning to adjust to the idea. I don't think we processed it either, I don't think we dealt with it certainly not mentally or emotionally. We were beginning to realise that this wasn't going to go away. It was something that we needed to learn how to cope with. Of course Adrian was doing a lot of online searching and me…I'm fascinated by all of that stuff, so I was doing a lot of reading up. My background is in biology as well, so I like to know how things work. I came across the NHS Choices website and going down that route of thinking well beta interferon is really the only option for any kind of treatment. How would that fit into our life? To inject myself once a week or once a day or once every three days: How would we do something as simple as go away camping if I have to take beta inteferon capsules with me and keep them in the fridge on the campsite. That kind of thing. It felt like the only treatment option, or non-option we wanted to take or that would fit into our life, which of course just meant there was no treatment!
Ad: The other issue for us when we started to look at beta interferon, a, they didn't actually seem to be that effective in terms of looking at what other patients, people with MS, were saying about their treatment and their experience of beta interferon, so on one hand they didn't seem particularly effective but the downsides and the side effects of beta interferon almost seemed to be as bad as some of the symptoms Helen was suffering anyway. It seemed very marginal as to whether there was any real benefit to beta interferon. I think partly the problem for me, looking at it at the time was, I was thinking about the then and now. I wasn't thinking in terms of how would beta interferon help in 5, 10, 15 years I was looking at it as a snap shot of this is where we are.
H: If it's going to help now then it's a good thing to do.
Ad: On balance it didn't really seem to offer that much benefit
A: Was that off-putting? The side-effects?
H: It was horrifically off-putting. It seemed like the treatment was worse than the condition. My symptoms were beginning to calm down. We'd got over that initial shock. I was still depressed and I still had a few tingles and stabbing pains and my general confusion is not good. I'm certainly not as focussed as I used to be but then I don't know whether that is age or the anaemia or the MS.
Ad: One of the things that excited us was that Alasdair Coles is such an enthusiastic person .One of the things he found interesting and engaging about Helen's particular range of symptoms was that there did seem to be high degree of activity within the brain and there seemed to be as many symptoms with regards to cognitive processing as physical. As a result one of the things we have found really is that stress in particular but just being constantly busy is probably the worst thing for Helen in terms of triggering symptoms. So when Helen stopped working and once we had got over the initial shock of the diagnosis and things had started to settle a bit and we had the initial contact with the hospital; that general lowering of background stress levels and being able to take things a little bit easier helped to dampen down all of Helen's symptoms to the point where Helen could think about it in the longer-term and consider what the options were and eventually wee started to talk about getting in touch with the clinic.
A: When did you get back in touch with the clinic?

H: It was probably between February and May 2006 and we phoned up and made an appointment. They were absolutely fantastic, regardless of what they could do, just to walk into a place where everyone understands what MS is, understand what effect it has on partners and carer, are endlessly enthusiastic and supportive and encouraging. It was such a relief to just be in touch with the MS clinic. We sat down and spoke to Alasdair and he listened to everything I had to say but more importantly for me he listened to what my partner said as well. Then he started talking about treatments. At the time there was a major Campath – beta interferon comparison trial going on. Initially he said that he'd put me on that and that I would be randomly assigned to either Campath or beta interferon. That made me a bit hesitant because I didn't want to have to go on beta interferon if there was something else available and from what Alasdair had told me about Campath and the fact that it was monoclonal antibody I was quite excited by it. Listening to the potential side-effects was a bit of a concern but I think having gone through a year or so of really quite aggressive MS, none of the side-effects sounded worse than what I had already been through.

A: What did he tell you about Campath and the benefits and the side-effects?

H: He said they weren't entirely sure yet but they were still working on what the full range of benefits would be but it did appear to be a better candidate for treatment then anything that they'd ever come across. In terms of reduction in the number of relapses, in terms of the severity of the relapses and also, tentatively, they had started getting indications that it had a long-term effect. It wasn't something you had to keep taking again and again. It was something you could have once and then wait and see and possibly have again and wait and see. In terms of MS treatments, it was just that was a major step forward.

Ad: A couple of things he was very clear about: One, it was not an ongoing treatment, so you might get a couple of goes at it but actually the body's reaction against Campath would mean it would stop being an option

H: You'd actually end up having antibodies against the monoclonal antibodies and Campath itself becomes an issue.

Ad: The other thing he was very clear about what that this was not a cure. You will suffer the same range of symptoms but hope fully no new symptoms and the symptoms you do suffer from will be less frequent and less severe.

H: One of the other things he was particularly keen to caution us about was that I had two autoimmune disease there was a huge chance that I would develop other autoimmune diseases. They did have other autoimmune disease popping up like ITP.

Ad; That was quite worrying on the basis that they'd had a bit of an issue in the States.

H: He gave us the patient information sheet and consent form and told us to take it away and think about it and we'll see you again in a month and then we can talk through it again and in that month someone in the State dies of ITP. Also that was the year that there was that big scandal about clinical trials because three people who had been on, I think phase 3 trials that were thought to be safe ended up dying and others with horrendous organ failure. T really was a major thing and of course my family found out about this and told me I couldn't go on a clinical trial because it was dangerous. That was another spike of anxiety and stress because of those

things. When we went back to Alasdair and he told us the Campath trials had been stopped, so whether I had wanted to go on it or not I couldn't at that moment.
A: And had you decided you wanted to go on it by that time?
H: I think even at that point I had decided that regardless of anything else I did not want to go on that specific trial because of the beta interferon potential and I really didn't want to go on beta interferon. Beta interferon felt likt one of those cures where once you started you had to keep on and given the drawbacks and down-sides I didn't think there was any point in starting, so what was the point in being on that trial. We kept on going backwards and forwards to the clinic once a month and they'd take blood, occasionally I'd have an MRI scan, we'd discuss new symptoms. By that point my symptoms were beginning to decline in severity and I hadn't had any new symptoms crop up in about 6 months.
A: So up until that point you weren't receiving any treatment?
H: No treatment whatsoever
A: So you were basically receiving just care and support?
H: Yes. I never saw an MS nurse and was not put in touch with any other specialists.
A: So you were just coping with the symptoms?
H: Yes. Going up to the clinic every month or so was the only support I got and it was so, so important.
A: You went to the clinic every month?
H: Pretty much. After that initial consultation in March 2006 we did keep going back. I think they were interested enough to keep in touch and I think they also realised that we needed answers and Adrian needed support as much as I needed support.
A: Would you see a neurologist every month?
H: I would see Alasdair once a month.
Ad: One of the best things about going up to the clinic during those months when we were deciding the treatment options was that it was the only time when the situation we were in seemed normal. We could sit and talk to Alasdair and various other members of the team and make light of MS and tell jokes.
H: It felt such a relief that there was someone on our wave length regardless of whether I got treatment or not. It was a normalisation process of everything we had gone through.
Ad: Up until that point everyone who we would mention it to would say "oh my God. That's terrible. What are you going to do?" That discourages you from even broaching the subject. It was the first time we could talk about it as though if it was just one of those things that happens without it being a major trauma. That was, certainly for me, so useful.
A: So the trials had come to an end when did things start back up again?
H: We turned up at the clinic in August 2006 thinking it would just be a question of blood tests and a chat but everyone was excited as it had all started back up again. Genzyme has a precursor treatment they wanted to try that was a non-binding form, so it introduces your system to something that isn't going to hurt it. So you would have, what they called, SM3 and then you would have Campath. It sounded very interesting. It was a very small trial – only about 20 people, which was a concern as there was a higher risk of things going wrong. But we decided we would go for it as I would be on Campath and also with the pre-treatment it was intellectually interesting. So in October 2006 I went in for three days of SM3 and then five days of

Campath the week after that. In October 2007 I went back in for another five days of Campath. So I've had Campath twice and SM3 once and they're the only treatments I've had.

A: When you were told about the side-effects of alemtuzumab and the risks associated with taking it did that change your willingness to participate in the trial? Did you think the benefits were enough to out weigh the potential risks?
H: Personally speaking the risks were significant but set against that idea in my mind that this wasn't a condition that was going to away. Although it's been horrific and is now okay-ish I was still having symptoms. I was still being reminded on daily basis that I had MS. I thought I know it's not a cure but if it helps with the symptoms and if it means this is as bad as it's ever going to get then I was willing to give it a go. We had built up a level of trust amongst the clinical team, I knew they weren't going to do anything to me that would really hurt me – apart from anything else they had their academic reputations to protect! It would be bad form to kill your patients! So I trusted them. I wanted to make sure that my condition got no worse and potentially got slightly better. I was thinking of the long-term – this was the first time that any treatment I had ever been offered that had the potential long-term benefit as well as immediate benefit. It was interesting because of the involvement of the SM3 pre-treatment it had potential well beyond just the alemtuzumab. There are so many monoclonal antibodies that if the SM3 part worked that would have major of implications for all sorts other conditions. I'm a strange old-fashioned person I think a lot about public duty. There was a sense of public duty. I have this condition, I 've been offered this treatment it's going to make my life better and it's going to make Adrian's life better if I'm better and potentially it has implications for a lot of other people.

A: What expectations did you have about alemtuzumab and the impact it would have on your life? What benefits and outcomes did you hope to gain from the treatment? What was most important to you?
H: I think the most important thing was that I didn't expect anything beyond freezing the condition where it was at. The only thing I expected from it was not to get worse.
Ad: The clinical team were to great pains to point out that was as much as they were hoping for. I think we based our expectations on what the clinic team said because we had such a degree of trust.

A: and that was most important to you? Stopping it where it was and not getting any new symptoms?
H: Yes. At the time I was still slightly depressed, I was still more fatigued then I had ever been in my life, I still had tingles and the occasional strange symptom, I still had cognitive fog but everything had reached a plateau and we were living with that plateau and we were coping with that plateau. I had gone back to work to a different job. I was working full time and I was coping okay with that. We were coping okay and it had stopped becoming the major focus in our life and became something we just had to take into account when planning anything. I just thought if we could freeze it at this level that would be liveable but if it continued to get worse then

we're going to have real problems, so at that point the idea of just not getting worse was a major thing.
Ad: This might sound a little trivial but part of that thinking as well was that we were very keen to move back to the south-west and the main reason we wanted to move back was the lifestyle. The fact that every evening, every weekend we were out on the moors, we were out on the beach – walking, cycling. The idea of going back to where we wanted to be geographically and live in an environment we loved so much and not be able to take advantage of it and go out and enjoy. That was a major contributory factor in terms of the decision. It would be a real shame to get back to where we want to be and not be able to enjoy it and sit and look at it from a wheelchair rather than actually be able to take advantage of it.

A: So you wanted to make sure you were stable and that your condition wouldn't get any worse before you moved back to the South-West?
H: Yes. It was future proofing our lives, if we can stop at this point, we know we can cope with it. If it only gets worse and I only have one or two more symptoms that's still something we could cope with but if my condition had continued to progress at the rate and the way that it had following diagnosis then it would've been untenable. I don't know what the end-point would've been but it wouldn't have been a good place, whereas it felt like alemtuzumab was giving me my life back. It was giving me a chance of having the life I had prior to diagnosis and without alemtuzumab I wasn't certain about what my life would've ended up being. Yes, it was scary. It was a horrific clinical trial. I mean clinical trials were in the news. It was scary. I didn't know what was going to happen. I didn't know whether I was going to react badly to it. The idea of being in hospital and being injected with stuff that was going to strip my immune system and rebuild it from scratch – it was serious messing around with my entire physiology and that was a terrifying thought.
Ad: My concerns were very much bounded by the information that we were given from the team, whereas Helen's background in biology gave her a better understanding of just how fundamental a treatment like this was in terms of it messing around with the building blocks of what keeps you alive.
H: Of course the implications of that are that you end up without an immune system, you're prey to any infection, already having two autoimmune conditions and the idea of potentially lessening the effect of one of those abut ending up with a different one was scary as well. Some of the other autoimmune conditions that I could've developed were possible even worse than the MS. The idea that it might not work; that I could go through all of that and it might not work was terrifying, and the whole procedure itself. Saying yes to alemtuzumab was less terrifying then living with MS untreated for the rest of my life. I could see a point in the future with untreated MS where I would probably say goodbye to Adrian and walk off into a field and take an overdose or something. I could see a point where it would become untenable to live with and I didn't want to get to that point.

A: Did you notice any side-effects as a result of alemtuzumab and were they tolerable
H: It was horrific! It's one thing to be told you're going to have a resurgence of some symptoms, that you might feel a bit tired, you'll get a strange rash. We were told

about some of the symptoms that other people who had just alemtuzumab had but to go through it was really difficult. I didn't go through the treatment alone, they give you a cellmate, so you all go through it with somebody else in the room who is also going through it. So you know whatever it is you're going through the person next to you is as well, which is kind of a comfort. We did do things like compare the rashes that we were getting. There was one moment where Adrian had turned up with a mug of coffee and I think I just fell asleep. I was absolutely shattered. I have never felt so fatigued in my life, even my eyelashes ached. I was that tired. By about day 3 of Campath I began thinking to myself that I had made a serious mistake as that was the worst I had ever felt in my life.

A: What was that like for you Adrian?
Ad: It was hard. I spent as much time at the clinic as I could. A great deal of that time I just sat by Helen's bed and held her hand. The team made it easier. The shock when I saw Helen the day after she was admitted she was covered in a rash, swollen, looked really very ill.
H: The cold sweats and the shivers. I thought I was going to shiver my bones to pieces. I was bundled up in so many blankets with a temperature of 104. I mean temperature was sky-rocketing but I could just not get warm.
Ad: It was tough to watch Helen have to go through it. I think the support of the team and the trust we had built up with the team really did help. If I hadn't had that relationship I probably would've been running all over the place asking what was going on.

A: How long did these symptoms last?
H: They were at their most intense whilst I was in hospital. When I when I went home I think I more or less just slept for the next couple of days.

A: How long were you in hospital for?
H: three days for the SMC and five days for each of the Campath infusions

A: Did you experience these side-effects at each dose?
H: Yes. Bizarrely it was worse when I took the SM3 and I wasn't suppose to react to that then it did with either of the doses of Campath but it was certainly worse with the first dose then it was for the second. When I went home I was asleep for two days and would then feel more or less okay. I was fatigued and certainly for two or three months after certain symptoms that I hadn't had for a while would come back. In a strange way it was like relearning my MS again from scratch. Then almost without noticing within probably two or three months of each dose that was it, I felt fine. To the extent that I wasn't meant to do anything that would challenge my immune system like eat brie or raw egg for quite sometime afterwards and we stuck to all of that advice but unfortunately the job that I was in – working for a University – didn't seem to have much of an idea….they didn't seem to understand the implications and so after both doses of Campath I actually ended up flying to the other side of the world to do work and coming home I got the worst cold I have ever had in my life because of course I had no immune system. To be honest the cold that I had within the month following Campath probably remained in my mind as the

biggest drawback of taking Campath. Apart from the fatigue, the revisiting of old symptoms that had faded away that was probably the biggest implication I had from taking the treatment - that and the blood tests! They, of course have their protocols for data gathering, so after each treatment you start off with a blood test every week for a month and then every month for six months and then every three months for a couple of years and then every six months for the rest of your life. It's a lot of blood tests and that really did get to the stage where it was getting difficult. I'd turn up to the doctors surgery, see the nurse and she'd say "Oh no, it's you again," we'd try and find a vein and she'd take some blood and then I'd see her again the next week and we'd go through the whole palava again. It is strange in that the worse things I can think of the alemtuzumab treatment either happened whilst I was in the hospital being treated or were more or less peripheral. They weren't physical or mental symptoms, they were catching spectacular colds, they were the trauma and the tediousness of going for so many blood tests, developing completely and totally out-of-the-blue allergies – one day I was fine with prawn and shellfish the next day I was violently allergic to them.

A: Which specific symptoms did you notice improvement with?
H: It was the peripheral tingles and pain. I no longer get tingly fingers or tingly legs, or tingly feet, the muscle spasms
Ad: The muscle spasms were really becoming quite a problem
H; But they more or less disappeared overnight
Ad: Losing the muscle spasms and the cramps was probably the most obvious
A: Are you still experiencing symptoms but to a lesser extent?
H: To be honest I do still experience symptoms but only when I know that I've overdone things. I see them less as symptoms then as warning signs. I know that I'm overdoing it if my fingers start tingling
Ad: It's about the fatigue ultimately. If Helen notices the fatigue is setting in and eases back then she can avoid other symptoms creeping in. If Helen pushes herself into the red zone then the symptoms do start to ramp up significantly.
H: Interestingly enough, we had a situation like that recently. The job I am in now is very, very stressful. I've had six months since our summer holiday and since then I have really, really stressed myself out. I couldn't turn my brain off, which then makes me fatigued and then I stop sleeping very well and that increases the fatigue and then I start getting symptoms. I knew we had to get to Christmas to get to our holiday. If I survived that long I got two weeks off by the time it got to Christmas I was absolutely exhausted but I stopped for two weeks and then I was fine. It's developed into a warning system. If I'm experiencing a symptom I know I need to have time off. It's given me more control I think of my MS.

A: Compared to your symptoms before alemtuzumab, are the symptoms now more manageable?
H: Hugely. When I get them they are minor niggles. They are completely manageable and I've had no new symptoms since I started Campath – nothing new at all and most of the old symptoms I've had haven't cropped up again.
Ad: That's not something we expected and not something the clinical team were expecting. Apparently it hasn't happened with everybody but a fair proportion of

people on the trial have experienced a significant degree of improvement. At the start we were told it wouldn't make anything better it would just stop anything from getting worse. We were both quite surprised at how effective it seemed to be.
A: Did it exceed your expectations
Ad: Absolutely
H: Yes. I took part in another extended trial which looked at the MRI scans of the brain and before alemtuzumab I had lots of brain damage and plaque and after the treatment there was none. I don't think in any of the MRI scans I had showed any plaques. Alasdair might say different but he never mentioned that I had any build up of plaques since the Campath.

A: In terms of the effect on your day-to-day life what impact has it had and what sort of activities has it allowed you do to?
H: I'm normal! MS, for me, has become a minor irritation that I have to take into account occasionally. For example, if I'm going away for work and I know it's going to be along intensive working session I'll book a week off afterwards. It's that kind of thing. It gives me a control of my life. I work full-time. I never thought at the time of diagnosis that I would be working, let along working full-time. I can work full-time in stressful jobs providing I take care of myself. I'm not fit at the moment but I know it's not going to be too much of a difficulty to do any physical activity that will help me get fit. I haven't done any of the studying that I want to do but my brain is working again. My brain isn't focussed exclusively on being an ill person anymore. It has given me my life back, it really has.
A: What effect has it had on you Adrian?
Ad: It has been very good. We are as close as being back to normal, before any obvious symptoms arose, as I think we're likely to get. It is still something that I have an awareness of and I find myself keeping track of Helen's physical and mental state much more closely now than I used to. I can't remember the last time I needed to get concerned or to intervene. I'd say we're 99% back to normality. It's brought out life back to as it was before diagnosis.
A: You said before that you wanted to move back to the south-west but you couldn't because of the MS, so what does this mean for your plans now?
Ad: Hopefully this year we are going to get out house on the market and start applying for jobs in the south-west. From that perspective, it has been fantastic. We don't actually feel like our lives are constrained anymore. It has been quite a relief. The only other thing I would say is that it has in certain respects it has drawn us closer together. We've been through an interesting time – about two or three years before we had been in a major car accident, which I was exceptionally lucky to walk away from. We had just got over that and Helen started to have symptoms from the MS. We've probably been through four or five years where we've been through some very difficult times and felt we had to fight our way through life on a daily basis. But not anymore. It really does feel just like a normal life.

A: So looking at the wide picture, not just related to you but the wider population, what do you think the difference would be for those people if alemtuzumab was made available on the NHS?

H: I feel so sorry for anyone, at the moment, that is newly diagnosed with MS. I think even now, 7 years after my own diagnosis, the choices for hope, for their future is so limited. It's a chronic, it's neurological and unless you're in a wheelchair no one really knows that you've got it. There is no overt support for those who are newly diagnosed. I don't think that many of the standard treatments, beta interferon glatiramer acetate, none of those options offer any hope. They're all maintenance. They're almost fobbing people off – you've got this, this should help, go away and don't come back. I think alemtuzumab and the new drugs that are coming out really are a glimmer of people being able to see beyond that treatment to a life where their condition will be manageable. I think putting people even slightly more control in of their condition is so important because they are going to be living with it until they die. We know from personal experience how traumatic it is to be diagnosed. When you're diagnosed with a condition that you are told is chronic and is never going to get better but keep on slowly getting worse and because of the nature of it, its very personal to you so your experience is not directly comparable with anybody elses. There is so much isolation, so much despair about whether it is normal, whether it is going to continue, am I going to end up with your symptom or that symptom. I think, at the moment, MS takes over people's lives and it becomes all that they are and I think alemtuzumab gives people a chance to be somebody who just happen to have MS rather than being MS themselves. It needs to be available as an option for anyone who is diagnosed they can't keep being fobbed with paracetamol, essentially.
Ad: I think the hope and just the awareness that things aren't going to get any worse is potentially a big thing on the part of carers. Something I really struggled with when we started going up to the clinic and made me very angry was being told by the staff at the clinic how fantastic I was that I was sticking by Helen. They spoke of the number of couples they saw where one partner had been diagnosed and as the condition deteriorated the well partner could see that progression resulted in the breakdown of that relationship because of the stress and the tension of seeing that. From a personal perspective there is absolutely nothing that would take me away from Helen other than Helen telling me to go away. It hadn't even occurred to me that leaving my partner because she had been diagnosed was even an option. When I first heard that happened there was just a part of me that wanted to go and hunt these people down. But I developed a better understanding that for some people seeing that lifetime of deterioration stretching out in front of them does put so much pressure and stress on the relationship and it certainly put stress and pressure on our relationship. But somehow we managed to get around that and come together. I do think with alemtuzumab that the hope that it gives. Although it is not a cure and it might not make things better but it will at least prevent that constant slide down. That's a big thing for partners and carers to be aware of.
H: I think the population of people who tend to be diagnosed with MS are young-ish – in their 20 and 30s – and are at the point in their life when you can see things opening up, you're possibly reaching the zenith of your career and you're thinking of having children, you're parents are getting older and you're beginning to have caring issues for other members of your family, you're possibly in a relationship that's been going on for several years and you might be thinking of getting married, having a house and decorating. All those things that make you an adult in society are

suddenly questionable, whether any of those things are going to happen. I mean are you going to be able to continue working? Do you want to have children and the stress of having children if you've suddenly been diagnosed with MS. Your partner might leave. If you can't work then your house is at risk. You might not be well enough to look after your parents. I mean having a diagnosis of MS is not just about the individual and their physical and mental condition; it's about the potential of that person is squashed or affected and just to be able to give people hope that all of those plans they had for the future might not have to be scrapped. Alemtuzumab gives them a way of controlling and maintaining and adapting and surviving their own chronic condition. It allows them to reevaluate and replan what they are going to do with their life. Obviously with any kind of chronic condition you have to re-evaluate what you can do and how likely it is you're going to be able to continue to do it. I think it is just so important to have a treatment that gives the hope that that re evaluation isn't going to have to be too much less than what you were hoping to do.
Ad: We met a lot of people over the years at the clinic and people who were not lucky enough to get Campath and I have to say the alternatives and beta interferon was the most common alternative didn't seem to give people the same sense of hope or optimism for the future
H: It's a daily or once a week reminder that you're a sick person because you have to inject yourself with something to stop being a sick person
Ad: Campath is not just positive for the person with the condition, it has wider benefits
H: It makes so much more sense to have a single slightly more expensive intervention in somebody's condition that makes them better for longer than to have a continual drip feed that doesn't work as well and is almost as expensive and doesn't have the same kind of long-term effect. You are always going to get worse with MS. There is no getting around the fact that it is a condition that will continue to deteriorate but if you can have a treatment that will initially stop that deterioration and it's postponed for longer in the future and when it happens again it's not so bad. Economically speaking, it's a no-brainer

A: What do you think the implications would be if NICE didn't approve the treatment and it wasn't made available on the NHS.
H: You are going to end up with generations of people who are thrown onto the scrap heap and given no hope. The implications of not having effective treatment are so much wider than the one person.
Ad: Broadly speaking, without Campath, I can't see that Helen would've been in full time work for the last five or six years
H: I probably would've been on disability living allowance and you (partner) would've been getting the Carers' allowance but more than that we would've given up. I may have been able to work part-time if I hadn't had the alemtuzumab but whether I would've done or not I think by that stage if I hadn't been treated and it carried on the way that it was I would've just given up.
Ad: If I was going to pick a sing word I think I would pick "optimism." Campath delivers that whereas beta interferon doesn't. When we've met people at the clinic who have been on beta interferon they are sustaining a life but they are not living,

which is very hard. One of the difficult aspects of Campath being so effective is that when we do meet those people you really do see that things could be a lot worse. Those people are trying very hard and living with a very difficult condition but you can see the life has been drained out of them and drained out of their partners and their families.

H: I'm actually a mentor for newly diagnosed people and people who are going through Campath treatment on a health and social website and I started and responded to a number of threads on alemtuzumab and I've been talking to a couple of people who had also been on Campath. It's got to the point now where we have to message each other privately because there are so many people in there who say "I have MS and my Physician, or my healthcare insurers, or my GP have told me that I have to take beta interferon or glatiramer acetate first before I can get anything else and I'm getting worse. It's horrific to be somebody who feels normal having had treatment going in there and saying to people that this stuff isn't actually available it's still in clinical trials and I'm one of the lucky ones. It's creating a two-tiered health system – some people happen to be lucky and if you happen to be lucky, if you happen to be in the right place and if you happen to have the right GP who puts you forward to the right consultant you might, just might be able to have a treatment that is effective otherwise screw you. That is not right

Ad: There is a degree of guilt on occasion when we look at people we think, "that should've been us"

Appendix B: A report on the perspectives of people with MS on relapses and disease modifying drugs

Multiple Sclerosis Society

Perspectives of people with MS on relapses and disease modifying drugs

MS Society

April 2010

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Authors: Riina Heinonen, Doug Brown and Ed Holloway

Executive summary

This report documents the methods and results of a 2010 MS Society survey of people with multiple sclerosis (MS) who have or have had relapsing-remitting MS. The purpose of the survey was to capture the experiences and feelings of people with MS in relation to relapses and disease modifying drugs (DMDs). The survey had three main sections with the first asking about experiences of relapses in general, second asking about experiences of DMDs that can be self-administered by weekly injections and the third section asking about experiences of Tysabri, a disease modifying drug that is administered monthly as an infusion in a clinic. In addition to multiple choice questions, the survey contained some free comment sections.

Relapses have repercussions that go beyond the physical symptoms – they hinder people's ability to work and carry out their day-to-day responsibilities, limit their independence and increase reliance on other people. Respondents were also worried about how a relapse would impact on those around them. Finally, relapses not only have a serious impact on the practical organisation of one's life but also on an emotional level with feelings of frustration and anxiety being common.

Issues related to difficulty of use were raised with both treatments. With injected DMDs the main concerns related to the injections themselves. People found injecting to be difficult and often had to rely on other people to help them with this. Injection site reactions were not only common but often very painful too. Other side-effects also appeared common and debilitating. The frequency of the injections means that life has to be planned around the treatment to avoid socially awkward situations and to ensure injecting can be done in privacy. Overall, the treatment impacted the person injecting, those close to them, and often the person's ability to carry out their responsibilities at work and elsewhere.

Issues related to Tysabri had a slightly different emphasis. Whilst the infusion itself appeared to be tolerated better than injections, travelling to get the treatment posed problems and the person receiving the treatment was consequently more dependent on other people. The more serious side-effects, namely the viral brain infection progressive multifocal leucoencephalopathy (PML) associated with Tysabri, caused this group of respondents to be more worried about side-effects.

The final question in the survey asked for respondents' preference for administering a disease modifying drug if three options were available: an infusion administered monthly in a hospital via a drip, self-administered injection given several times a week and a pill taken daily. The overwhelming majority (95 per cent) chose the pill option, giving ease of use, convenience to everyday life and non-invasiveness as reasons for selecting this option.

The responses illustrate the practical impact relapses and using disease modifying drugs can have on a person's everyday life, giving a clear idea what

respondents would like to see improved. Both forms of treatment have strengths and weaknesses, and by identifying these strengths and weaknesses the report will draw a picture of what people with MS would want from a treatment.

The responses indicate that there was a preference for a therapy that would allow people to be in charge of their own treatment and would enable them to be independent in this sense. The treatment would easily fit in a person's everyday life and normal activities and would not have debilitating side-effects. The treatment would enable the person to carry on with their normal life, to stay in paid employment and be able to care for their family and rather than being cared for.

1. Introduction

This report documents the methods and results of a 2010 MS Society survey of people with MS who have or have had relapsing-remitting MS. The purpose of the survey was to capture the experiences of people with MS in relation to relapses and disease modifying drugs (DMDs). Although information is available about relapses in general as well as the side-effects of disease modifying drugs, it was felt important to try and gain an understanding of what people themselves thought were the problems they have to face, what they go through during a relapse and what their own experiences of taking the DMD was. The survey was designed by the MS Society Research and Policy teams.

This chapter will give some background information about MS, what treatments are available and which treatments are expected to become available in the future. After this there is a brief section describing how the survey was carried out. The rest of the report will discuss the results of the survey.

1.1. What is multiple sclerosis?

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.

The causes of MS are unknown, though it is widely believed to be caused by a combination of genetic and environmental factors. Several genes have been associated with increasing the risk of developing MS and it is estimated that there could be as many as 50-100 genes linked to the condition. There is also some evidence linking a number of environmental factors to MS such as viral infections and vitamin D deficiency but the relative impact of these on causing the condition is yet to be determined.

There are four main recognised types of MS:

- Relapsing-remitting MS (RRMS): Characterised as periods of relapse (acute MS 'attacks') followed by periods of remission (complete or partial recovery). Around 85 per cent of people are diagnosed with RRMS.
- Secondary progressive MS (SPMS): Following an initial period of RRMS, many people develop SPMS which is characterised as a gradual accumulation of disability, either with or without relapses.

- Primary progressive MS (PPMS): Characterised as a gradual accumulation of disability from diagnosis with no distinct periods of relapse and remission. Between 5 and 15 per cent of people are diagnosed with PPMS.
- Benign MS: Is diagnosed if the condition has not got worse over a 10 to 20 year period and is associated with little or no disability.

There are many symptoms associated with MS, which include restricted mobility, chronic fatigue, bladder and bowel problems and cognitive impairment. MS is unpredictable and affects people in very different ways, with variability in severity, in rates of progression and in type and severity of symptoms. This unpredictability results in a major impact on the quality of life of people with MS and can often lead to periods of significant disability.

What are relapses?

Immune damage to the myelin sheath is believed to cause relapses, or MS 'attacks'. Clinicians define a relapse as an episode of neurological symptoms, lasting for at least 24 hours, that happens at least 30 days after any previous episode began. In relapses, symptoms usually come on over a short period of time and often remain for a number of weeks, but sometimes months. Relapses can vary from mild to severe. At their worst, acute relapses may need hospital treatment, but many relapses are managed at home, with the support of a GP, MS specialist nurse, and other care professionals.

Due to the varied and unpredictable nature of the condition determining an 'average' relapse rate for RRMS is not straight forward and is an issue that has caused much debate amongst the clinical community. Although a true consensus is yet to be reached, the many thousands of people currently on disease modifying drugs (DMDs) indicates that it is likely that a significant proportion of people with RRMS experience 1 or more relapses per year

Current treatments

There are four classes of DMDs licensed for RRMS and none licensed for PPMS or SPMS. The DMDs licensed for RRMS include 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. These are usually prescribed to people that have experienced two or more relapses over a two year period. The precise way these DMDs work is unclear but they appear to modulate the immune system in a way that reduces the damage caused to myelin. It has been shown that these DMDs reduce relapse rates on average by 33 per cent; there is limited evidence on their long term effect on disability progression. There are a number of side effects associated with these DMDs that have a significant impact on quality of life, including injection site reactions and flu-like symptoms.

Natalizumab is a monoclonal antibody treatment delivered by monthly infusion in a hospital clinic. It is prescribed for highly active RRMS where either the relapse rate or severity of relapses is considered high. Natalizumab works by preventing the immune system cells, that cause the damage associated with MS, from entering the central nervous system thereby preventing the damage to myelin. It has been shown that natalizumab can reduce relapse rates by around 67 per cent and can reduce the risk of disability progression by around 40 per cent. There are a number of side effects associated with natalizumab the most serious being a one in a 1000 risk of developing PML, a viral infection of the brain which can often lead to death.

73 per cent of the respondents to this survey had taken one or more of these drugs. As will be shown later in the report, this group of people have a wealth of first-hand experience of the benefits but also the down-sides of these treatments.

Treatments on the horizon

There is a huge need for better treatments for MS. There is no cure for the condition and no DMDs for non-relapsing progressive forms of MS. Although there are available treatments for RRMS their effectiveness is varied and the side effects can be significant.

There are a number of new potential treatments on the horizon that, from clinical trial data, look to be at least as good as if not potentially better than existing treatments. The first wave of potential new treatments for RRMS include the oral therapies, cladribine and fingolimod, that act on the immune system. Clinical trial data suggests that these reduce relapse rates by around 50 per cent. As with all DMDs these do have side effects, but they are available as a pill thereby eliminating the need to self-inject and therefore eliminating injection site reactions – a common side-effect of injecting.

The second wave of potential new treatments for RRMS may include more powerful monoclonal antibodies that suppress the immune system. These include alemtuzumab which, although associated with a number of side effects, appears to reduce relapse rates significantly and reduce disability progression by around 70 per cent, even reversing disability in some cases.

The next wave is difficult to predict but it is likely to include potential new treatments that will look to promote the repair of myelin or protect nerve fibres from damage rather than having an effect on the immune system. A combination of this type of treatment with a treatment that acts on the immune system may help in significantly reducing the effects of MS in the long term; however, this is the vision of future MS treatment which is not likely to become a reality for many years.

This report concentrates on the treatments that are currently available, betainterferons, glatiramer acetate and natalizumab.

1.2. How was the survey carried out?

Administration of the survey

The questionnaire was available online (at surveymonkey.com) from 26th March until 14th April 2010 and was advertised on the MS Society website and intranet. Information and a link to the questionnaire were also emailed to all MS Society area teams and to the directors of MS Society Northern Ireland, Wales and Scotland who all distributed the information as they saw fit. Information and a link to the questionnaire were also posted in MS Society's Facebook page (with 5000 fans) and sent to 3000 Twitter followers, and included in the Campaigns eNewsletter and MS Society eNewsletter.

Inclusion and exclusion criteria

The total number of respondents was 1129. However, only those who had or had previously had relapsing-remitting MS or who had benign MS were included in the study, whereas those who did not have MS or had primary progressive MS were excluded from the survey. One of the options in the screening question was "I have MS but do not know which type", these responses were also included. Finally, surveys that were only partially filled in were also excluded. The total number of responses included in the analysis was therefore 1007.

The average/typical respondent was female (73 per cent of all respondents), was aged between 31-50 (67 per cent), and had RRMS (80 per cent). They had experience of taking at least one of the disease modifying drugs (73 per cent). For distribution of type of MS and age of the respondents, please see figures 1 and 2 below.

Figure 1

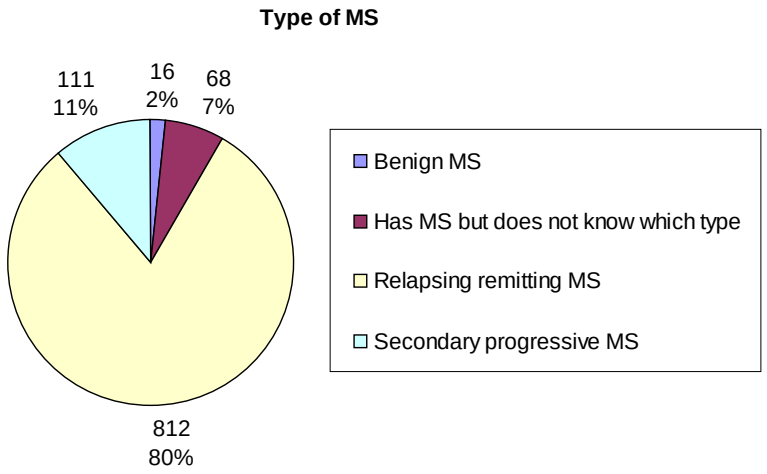
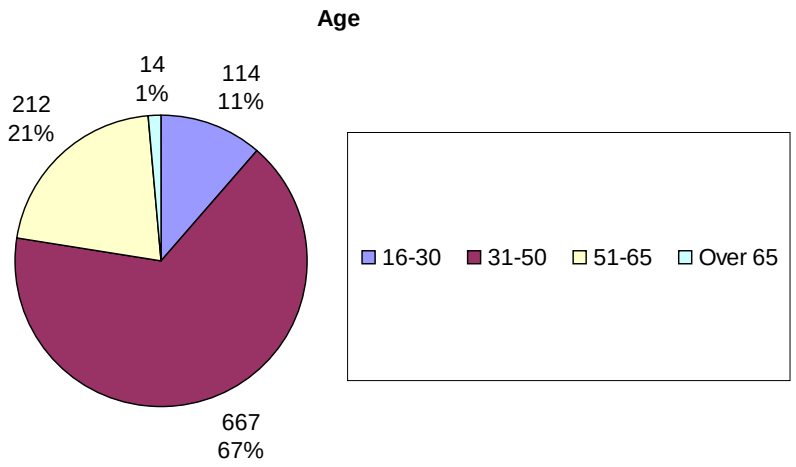


Figure 2



Analysis

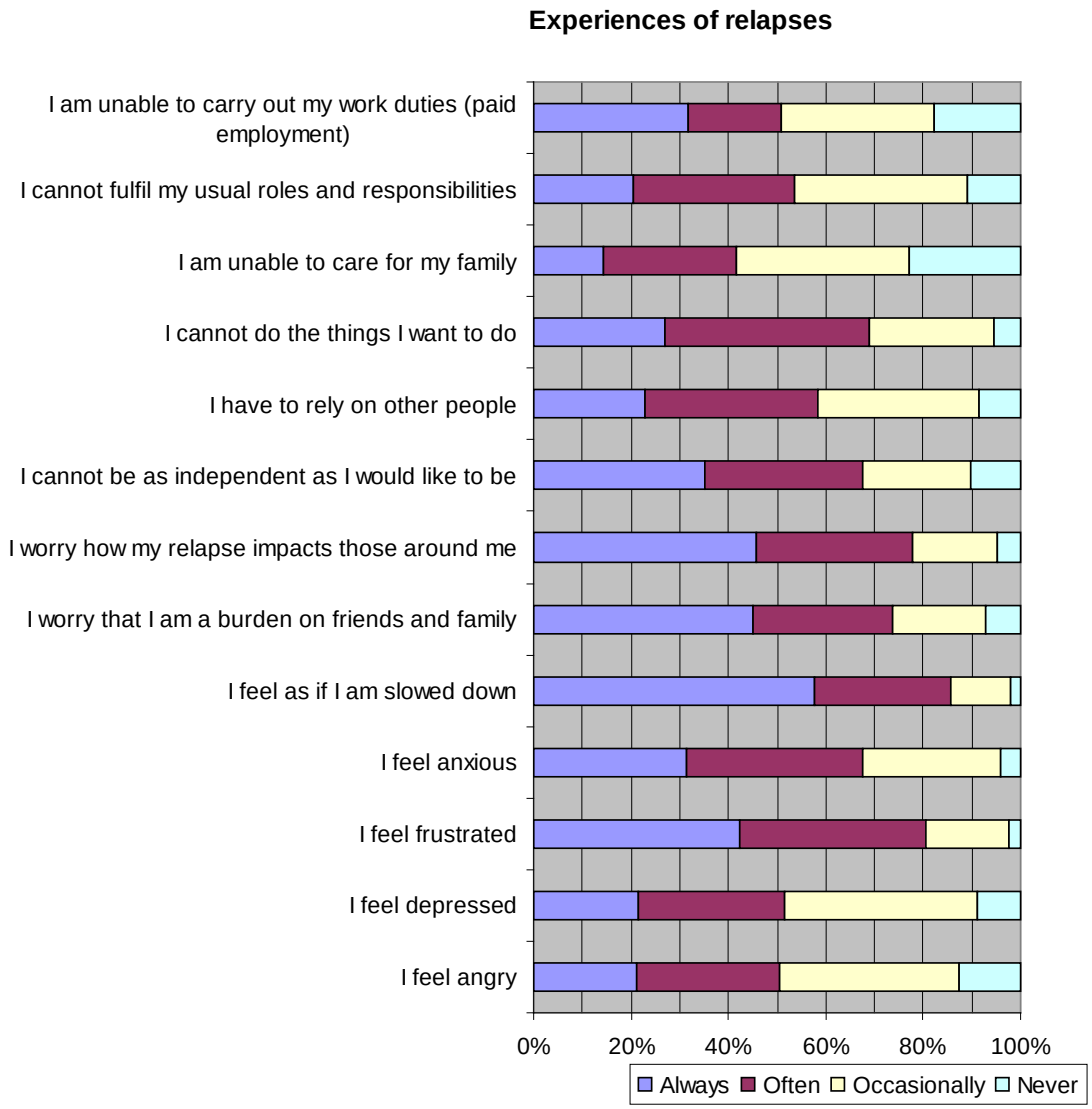
Descriptive statistics were used to analyse the results of the survey. Due to rounding, the percentages for each questions do not always add up to 100 per cent. Quotes from the free comment sections were extracted to illustrate the results of the survey, but no systematic analysis was conducted on the free text answers.

2. Experiences of relapses

All those who qualified to take part in the survey were asked about their experiences in relation to relapses. The total number of respondents for this section was 1007.

The respondents were first presented with statements related to relapses and asked to rate them according to how closely the statements reflected their own experiences. The response options were ‘always’, ‘often’, ‘occasionally’ and ‘never’. The statements ranged from ones dealing with the practical impact of relapses on the respondents’ everyday life to ones scoping emotional impact of relapses. The statements and the distribution of responses to them are presented in the table below (figure 3).

Figure 3



Work and other responsibilities

On being asked whether a relapse prevents the respondent from carrying out their work duties (particularly in reference to paid employment), the most frequent response (32 per cent) was ‘always’ (Figure 3). If response categories ‘always’ and ‘often’ are combined, over half of the respondents (51 per cent) reported that a relapse has an impact on their ability to carry out their work duties.

The impact of relapses on work was also reflected in the answers given in the free comment section:

> *“Relapses make sustaining full-time work so much more difficult as they make each day such an effort and I am exhausted, although I still manage to hold down a responsible job.”*
>
> *“I had two relapses last year one straight after the other. These relapses can be very debilitating and take away your independence. I work part-time and when I have to have time off sick I feel I am letting people down. I am currently undertaking light duties as my mobility is not what it was. This upsets me greatly as I feel that due to MS I am unable to do the job I have enjoyed for many years.”*

The difficulties of holding on to one’s job were also visible in the responses. Adjustments are sometimes needed to enable someone with MS to stay working. This was clearly something where some respondents were more fortunate than others:

> *“I am lucky that I have an understanding employer who has agreed for me to work from home part of the week and when I am having problems (mobility wise). This I have found very useful, helping me from a fatigue point of view as well as allowing me to continue to work.”*
>
> *“I try to limit the impact at work by taking annual leave instead of sick leave if I feel I am losing energy which means I spend a lot of annual leave in bed recovering from work.”*
>
> *“I have had 4 bad relapses in the last 14 months causing me to have to take 6 months off work in total. I have now been made redundant and wonder if it was because of the disability?”*

18 per cent of respondents indicated they were never unable to carry out their work duties due to a relapse. It is worth noting that unemployment among

people with MS is higher than in the general population, and this might go some way to explain the number of responses in category ‘never’.

Finally, being unable to carry out one’s responsibilities is not just restricted to employment. When asked about fulfilling one’s roles and responsibilities in general, over a half of the respondents (53 per cent) thought they were ‘often’ or ‘always’ unable to fulfil their usual roles and responsibilities because of a relapse.

Independence

Some of the statements scoped respondents’ perceptions of independence in relation to a relapse. Overall, the great majority (some 91 per cent) felt that they have to rely on other people at least occasionally, with nearly 60 per cent reporting they had to rely on other people either always (23 per cent) or often (35 per cent).

> *“I have had awful relapses, where I have been unable to do anything for myself for months, until relapse passes, leaving you weak, feeling dreadful and depressed.”*

> *“If there was a high risk treatment which could potentially cure my MS I would seize the opportunity with both hands as I want to be normal again and not have to endure debilitating relapses several times a year, which set me back so far and mean I have rely on others to help me, when I just want to be able to do the things that everyone else takes for granted.”*

> *“I have persevered with the inconvenience of injections because the relapses would be worse. The injections require a bit of planning and some symptoms on the day of injection, but I feel this is worth suffering to minimise the likelihood of another relapse, and the inevitable worry and complete dependence on family to care for me that would result.”*

When presented with the statement “I cannot be as independent as I would like to be”, 35 per cent of respondents felt that this reflected their experience always, with a total of 89 per cent of respondents feeling that this reflected their experience at least occasionally.

> *“I found relapses very frightening and upsetting, having to take time off work, deal with new symptoms, losing control of my life and independence and the uncertainty of not knowing what residual damage would be left when the relapse ended.”*

Worry about other people

There were two statements scoping whether respondents were worried how their situation impacts those around them. It was very clear that this was a concern to many, with 46 per cent indicating they were always worried about how their relapse impacts on others and 45 per cent saying that they always worrying that they are a burden to their friends and family.

A relapse does not only affect the person with MS but also those around them.
Particularly with a reduction in independence, families are often closely involved with care but the relationship can become strained under concerns for a loved one, the carers own needs and the unknown:

> *"Relapses change your life completely - not the same person at all any more. DMD are difficult to handle at time because of the bad side effects (not each week but for me I would say 3/5 weeks are a problem to me and I have had to live my life around this which is sometimes difficult, not only for me but my family too."*

> *"Relapses are not only worrying, painful & distressing at the time but can take a considerable amount of time to recover from, I have been left with residual problems from every relapse. I then worry about the impact on my husband and that he has to take time off work to help me. The concern that he will not cope if I become severely affected by another relapse is a genuine worry as he gets extremely frustrated with the whole MS scenario. As a very independent person this adds it's own issues to my state of mind, as well as the fact that I cannot be there as readily for my children and colleagues."*

> *"I am fortunate that I haven't had to take drugs as yet but I do know that relapses make me feel awful and debilitated and it is very hard to explain to you family why you feel like you do."*

> *"It has never got any easier to inject myself or any easier to ask my husband to do it for me. Indeed it can cause friction between us because we both get anxious."*

Emotional well-being

Finally, there were several statements relating to general feelings during a relapse. The feeling of being slowed down was certainly one that respondents recognised, with a majority of 58 per cent claiming this to reflected their experience always. The feeling of frustration also seemed to closely reflect the respondents' experience of a relapse, with 42 per cent saying this was the case always and a further 38 per cent saying this was the case often. Finally, feeling anxious reflected nearly 67 per cent of respondents experiences either always or often. The feelings (anxiety, frustration, depression) can stem from a number of things:

> *"I feel frustrated as I am very independent and I am very scared losing functionality."*

> *"Due to the change in feeling in my legs I no longer felt safe to work in my original job role when diagnosed therefore left for an office job. This lead to an episode of anxiety and mild depression which still bothers me from time to time."*

"I felt extremely nervous and frightened when first told I would need to take the drugs - I became depressed at this time as the enormity of my diagnosis hit home, that this was it for life until the drugs stopped working."

"I suffered Post-natal depression which stemmed from my absolute fear of having a relapse and not being able to look after my child. This was coupled with anxiety attacks caused by fear of not getting enough sleep, becoming run down and then having a relapse. This desperately impacted my first 8 weeks after birth, which I'll never get back."

Relapses have repercussions that go beyond the physical symptoms – they hinder people's ability to work and carry out their day-to-day responsibilities, limit their independence and increase reliance on other people. Respondents were also worried about how a relapse would impact those around them as friends and family are also affected by the uncertainty of the condition. Finally, relapses not only have a serious impact on the practical organisation of one's life but also on a person's emotional well-being.

3. Experiences of disease modifying drugs

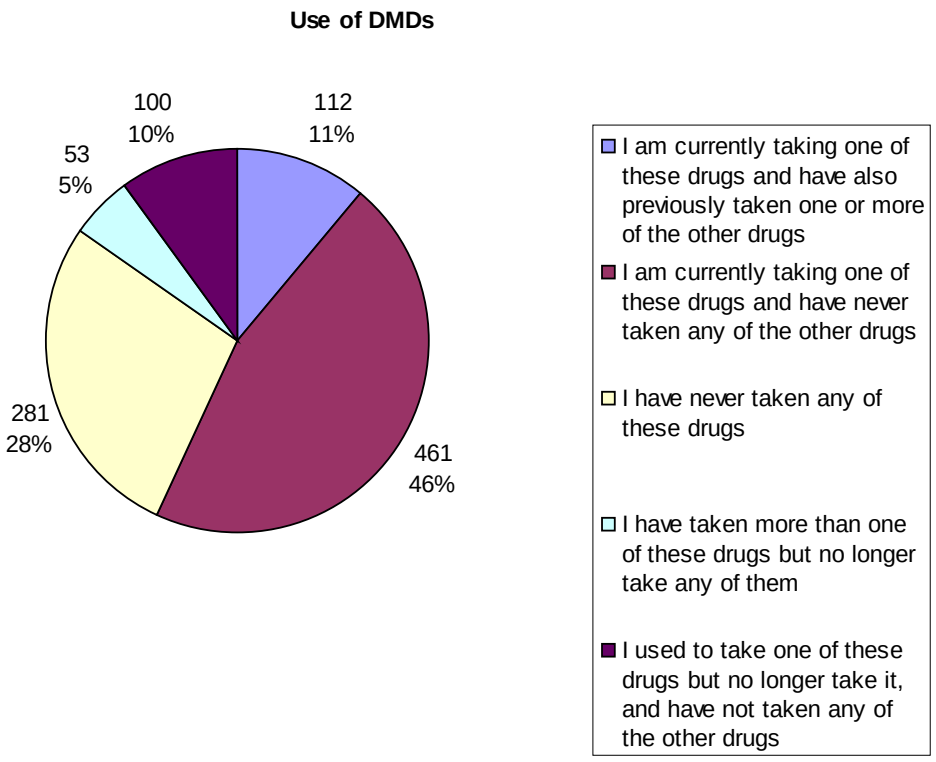
The survey also sought to find out about experiences specifically related to injecting disease modifying drugs (Avonex, Rebif, Betaferon, Extavia or Copaxone) or taking Tysabri. People who had experience of using at least one of these drugs at some point were invited to answer these sections, whereas those who had not used either at any time were excluded from this stage.

Overall, 73 per cent (N=736) of the respondents had taken at least one of these disease modifying drugs at some point in time.

3.1. Injecting disease modifying drugs

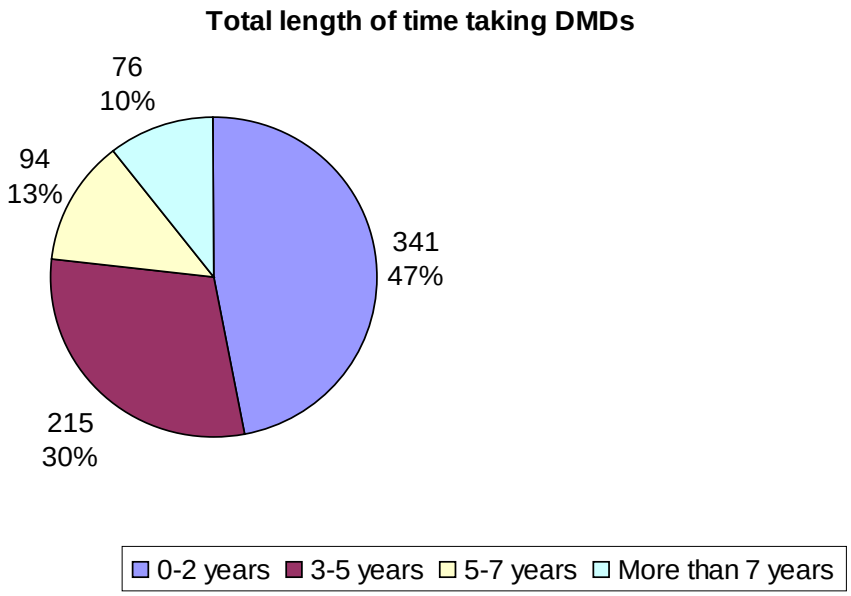
72 per cent of the respondents had taken at least one of the injected DMDs at some point in time. Of those who responded to this section, 57 per cent were currently taking one of these DMDs. 15 per cent of the respondents had tried at least one of these drugs but were no longer taking any. 26 per cent had discontinued taking one of these drugs earlier on (figure 4). Reasons for discontinuing drugs are discussed further below.

Figure 4



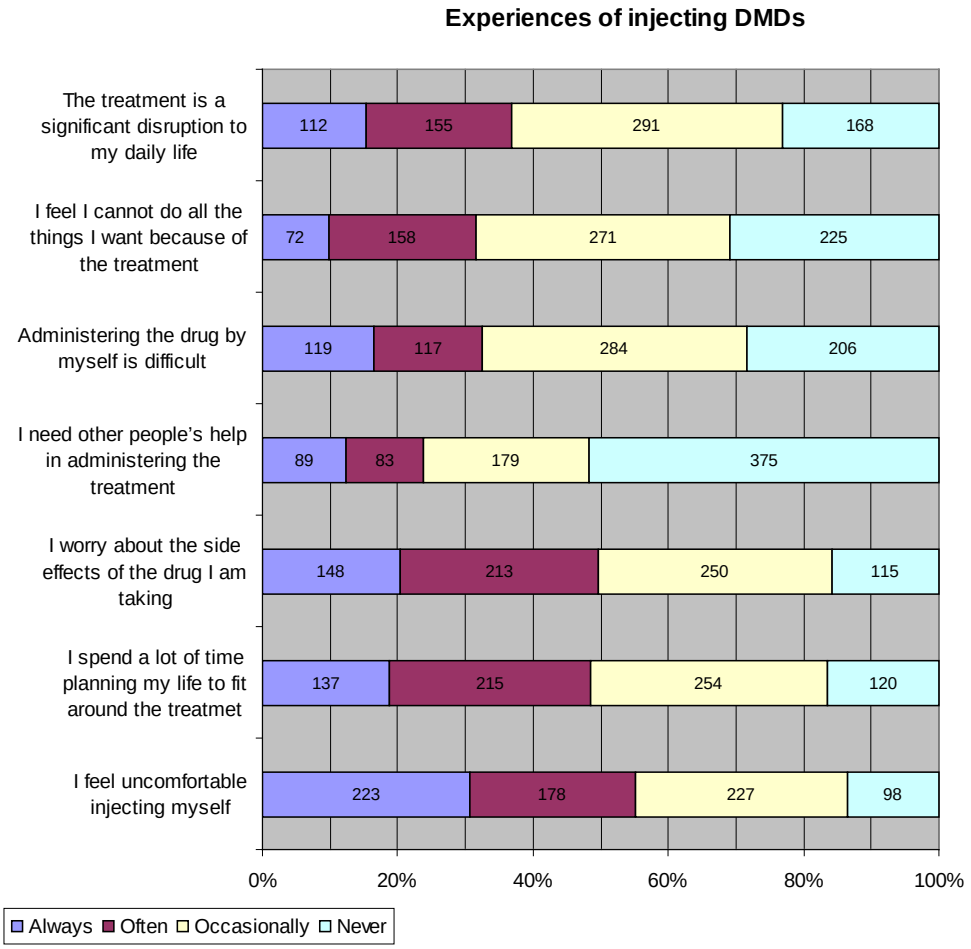
For a breakdown of the length of treatment on injected DMDs, please see figure 5.

Figure 5



Respondents were presented with statements about practicalities and experiences of injecting DMDs, and asked to rate them on a scale of Always-Never, according to how the statements reflected the respondents' experiences. Please see figure 6 below for the statements and the distribution of responses.

Figure 6



Independence

Over half of the respondents reported that they never needed other people's help in administering (mixing etc.) the drug and in a separate statement, 28 per cent found self-administration never to be difficult. Although it should not go unnoticed that there were also a significant proportion of respondents who found these areas problematic at least at times, it appears that self-administering the drug allows for more independence. This was certainly the view of some of the respondents:

> *"I would not want to go to hospital monthly for a drip – you spend enough time there or with other medical professionals. It isn't just the the time it takes for the drip, it's the recovery time too and having someone to go with you."*

> *"I feel very lucky to have the ease of use with the Rebismart and not having to be the 'patient', I can do all of my injections myself. However, my arms and legs are dotted with skin reactions, when I wear a swimming costume on holiday, I feel I need to cover up all the time. I would welcome an oral drug, so long as the side effects were similar, so that I could lead a more normal life."*

Independence enabled by self-injecting becomes even more apparent when compared with Tysabri which cannot be self-administered, and this will be discussed later in the report.

While injected DMDs may be easy to administer without other people's help, nearly 50 per cent of respondents thought they spent a lot of time planning around the treatment either always or often (figure 6). The need for planning is well illustrated by the comments describing everyday situations that are familiar to everyone, but that become problematic when you have to fit in everything that goes with the treatment:

> *"Needing to give myself an injection after a long day (e.g. after a party, night out, long journey) can be difficult. Carrying all the paraphernalia - cool box, injector, sharps box, et al - when going away can be a nuisance, frankly. Finding somewhere private to inject isn't always easy. I can't inject in some parts of my body myself, so need to rely on someone else (who isn't always around)."*
>
> *"It does involve planning when going on holiday as a fridge is needed in hotter climates, airlines need to be notified and delivery company contacted."*
>
> *"There is also the hassle of keeping the drug in the fridge (away from the children). There is all the paraphernalia with the equipment needed. Sharps box, auto injector. Having to think about taking it all on holiday. Will there be a fridge to keep the Rebif in? A place to store it at home. Being in when the delivery van comes every month."*

Although self-administered DMDs appeared to allow for more independence, they also have their problems, and need some planning to be compatible with an active life.

Injections

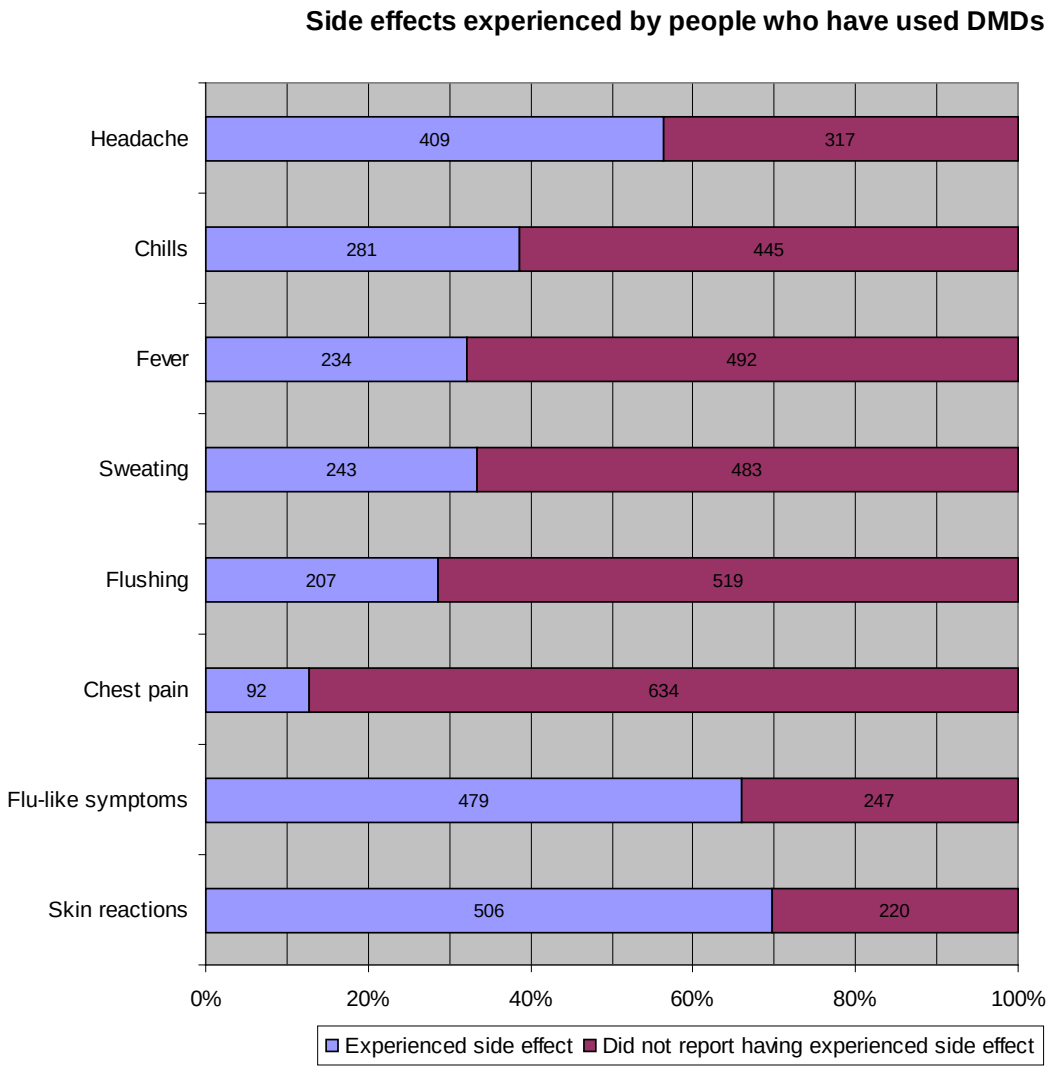
A little over 31 per cent of respondents felt always uncomfortable about injecting oneself. Overall, nearly 90 per cent of the respondents reported feeling uncomfortable injecting at least occasionally. The self-injection, which many respondents found difficult, featured often in the comments:

> *"It is a frightening thing being told that DMDs are only available via an injection and that you have to do it. To begin with, it controls your life as it is against human nature to hurt yourself and even trickier when trying to inject with a tremor."*
>
> *"Injecting daily is both painful and inconvenient. It is something that daily I dread."*
>
> *"It's not pleasant experiencing the flu-like symptoms, but I think this would be far easier to cope with if you didn't have to inject as well."*

Side-effects

In addition to the difficulty of injection itself, injection sites can develop painful skin reactions and this was the most commonly experienced side effect, as reported by 70 per cent of respondents (see figure 7). Other commonly experienced symptoms were flu-like symptoms (66 per cent) and headache (56 per cent). Overall, 64 per cent of the respondents had sought some form of medical advice because of the side-effects (figure 8).

Figure 7



It is not surprising then, that nearly 50 per cent of respondents said they worried about the side-effects often or always (figure 6). The impact of the side-effects was described in the free comments:

> *"I am a young woman and I feel this disease limits my life in ways it should not, I want to take my medication to stay well but I hate having to take injections, they hurt and make a mess of my skin."*

> *"Sometimes the side-effects are worse than the symptoms of a relapse."*

“I take a weekly injection. I don’t suffer strong side effects but the following day is a bit of a write off - like a minor flu, tiredness and headaches etc and difficulties in concentrating. I can do very little on that day. To help ensure I can continue with work I inject on Friday evenings which means that I get a 1 day weekend (the Saturday being a write off). I live with this but it can be very tiring and draining - physically, mentally and emotionally.”

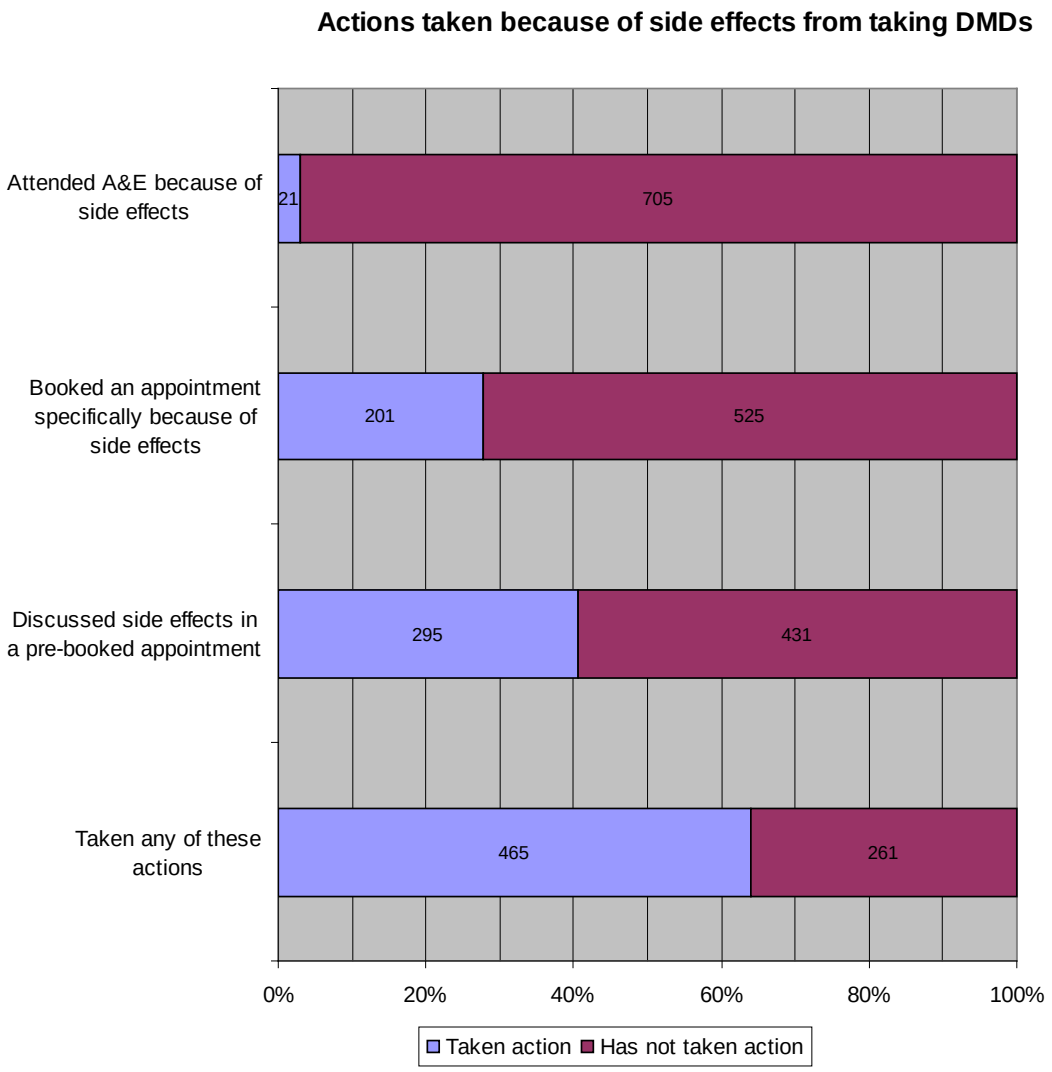
Finally, those who had discontinued one of these treatments at some point were asked for a reason for this. Common reasons were to do with the side-effects, fear of needles and ineffectiveness of treatment. Skin reactions was a side-effect that was particularly singled out and reported frequently as a reason for discontinuing a treatment.

“I found the self injection too stressful. I could not come to terms with it having a deep fear of needles.”

“I couldn't inject myself. It was taking over everything else in my life!!”

“I hated the needle, the bruises and needle marks and the side effects.”

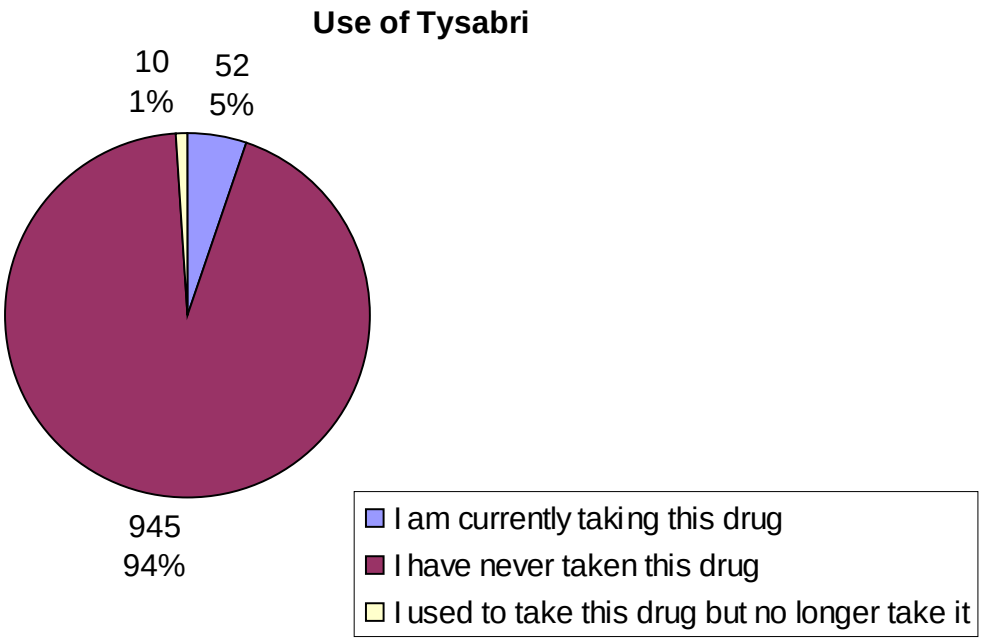
Figure 8



3.2. Taking Tysabri (natalizumab)

Tysabri is the brand name for natalizumab, a disease modifying drug recommended by NICE for adults with “rapidly evolving, severe, relapsing-remitting MS”. Unlike injected DMDs, Tysabri cannot be self-administered but is given as monthly infusions by a health care professional.

Figure 9

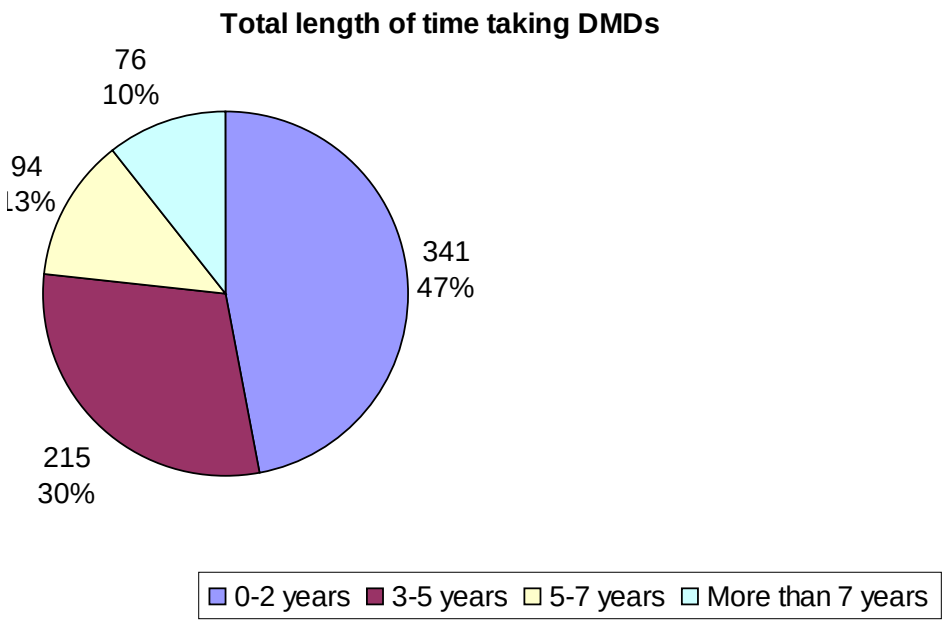


The number of people using Tysabri (figure 9) is lower than the number of those using injected DMDs and this was also reflected in the number of responses to this section – a total of 62. Of the 62, 52 were currently taking Tysabri and a further 10 people had taken Tysabri at some point but discontinued the treatment. Reasons given for discontinuing the treatment were risk of PML, a viral brain infection that can be fatal, and clinician's decision. There has been one large study suggesting that the chance of developing PML for someone using Tysabri for 18 months is around one in 1000. This study looked at over 3400 people taking natalizumab, but they did not all have MS. The risk of PML with Tysabri use increases after 2 years of therapy. The long-term risk is thus not yet known, but it seems this risk might affect decisions about treatment as the following comment exemplifies:

> *"I have been told by my consultant that I have to come off tysabri by the end of this year, so getting new treatments licensed as soon as possible is important because tysabri has changed my life for the better and to lose that is going to be very hard. The only thing is that I have been told that I have to be off tysabri for a minimum of six months so not looking forward to that period with no meds."*

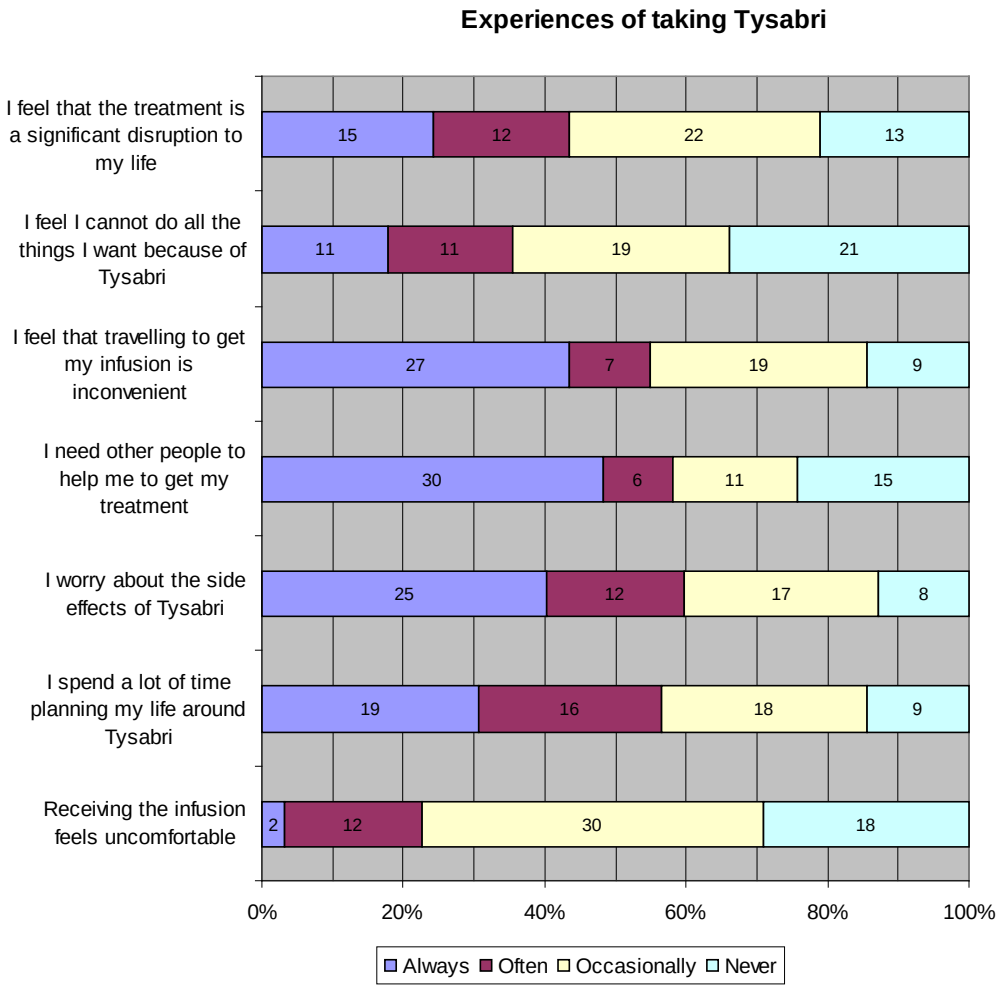
For a break-down of the duration of treatment with Tysabri, please see figure 10.

Figure 10



The respondents were presented with similar statements scoping experiences of being on Tysabri, as in the section about injecting DMDs. The statements were modified to better reflect the practicalities of Tysabri-taking, whilst keeping them as similar as possible to enable comparison (see Figure 11).

Figure 11



When comparing the responses to statements between the two different types of disease modifying treatment, some interesting differences emerge. For the distribution of responses related to Tysabri, please see figure 11.

Practicalities around Tysabri, which is administered monthly by a health care professional, are very different from self-injecting. Receiving one's infusion requires the person to travel to a hospital or a clinic, and this was found to be inconvenient with nearly 50 per cent of respondents finding this to be the case always.

> *"Early days for tysabri. the main difficulty is the travel to hospital (but maybe i'll get used to that) and the time off work required for the treatment. but I remain hopeful."*

> *"Shame I wasn't forewarned of how long the hospital visit would take (patients are told 1 hour infusion + 1 hour obs - first visit was 7.5 hours, subsequent ones never less than 4 - not a problem now I know to take packed lunch + work, but very annoying on first visit when I was unprepared)"*

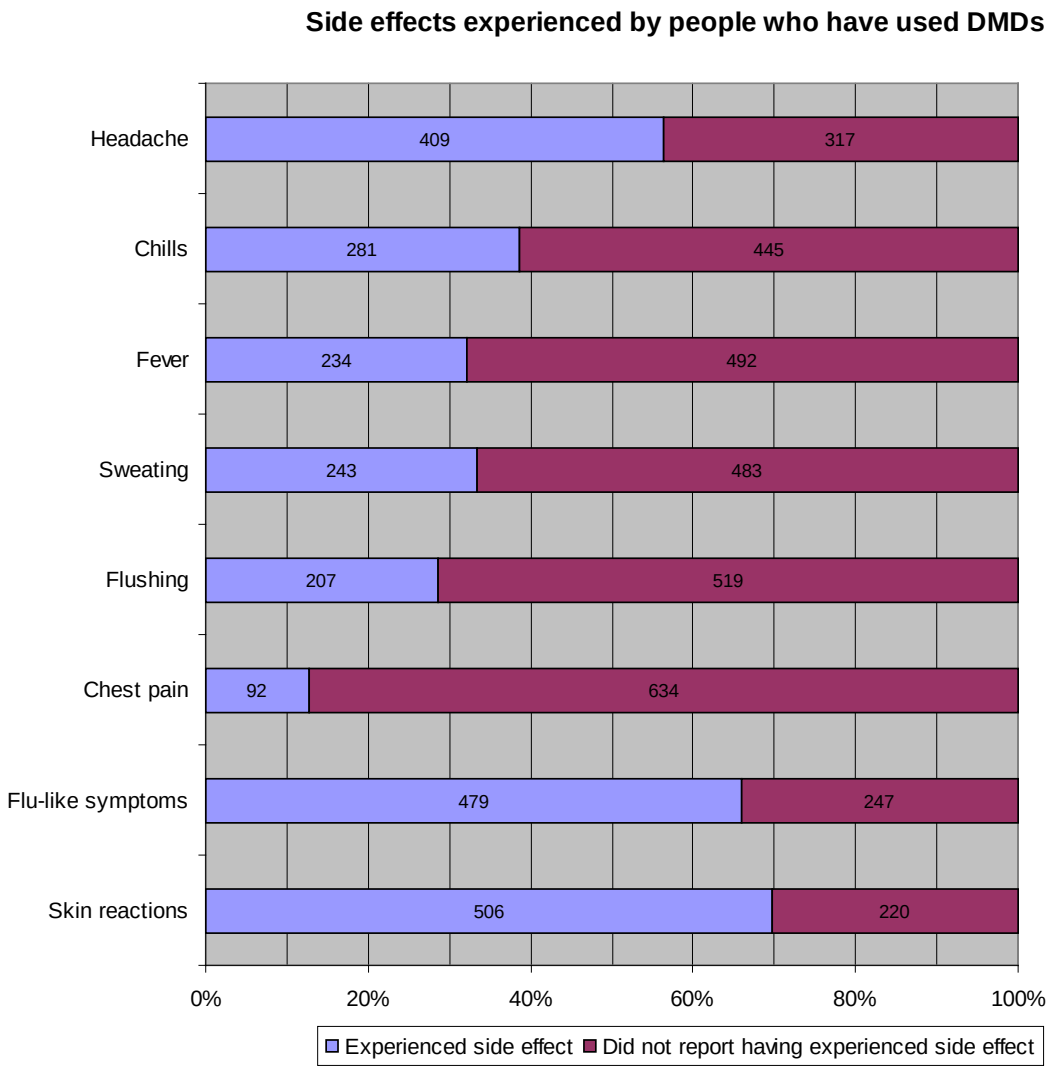
> *“Copaxone has left 'dipping' all over my body, (legs on both sides, buttocks on both sides) and although Tysabri seems to be working, although it does take two days out of my month.”*

There are some side-effects, such as shivering, feeling sick or dizzy, that can be experienced during or directly after the infusion. There were similar statements asking about discomfort for each of the treatments – the one asking about feeling uncomfortable when receiving the infusion and the other whilst injecting. 22 per cent of respondents felt receiving the infusion felt uncomfortable either always or often, and this was relatively low compared to the discomfort of the injecting oneself with 56 per cent reporting this to reflect their feeling always or often. Whereas problems and discomfort of injecting were commonly commented, there were no comments made about the discomfort of infusions.

Side-effects

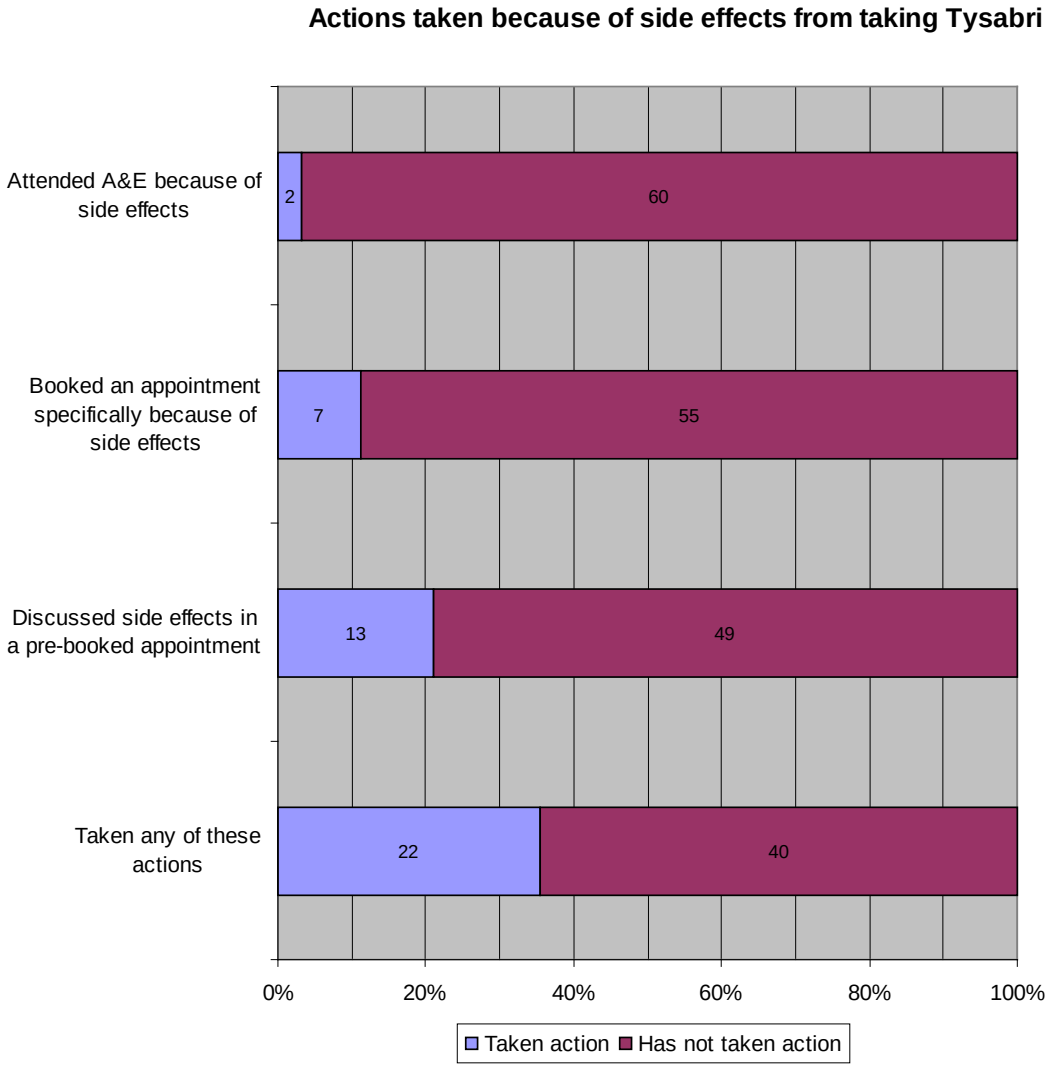
The most common side effects experienced after taking Tysabri are joint pain, fever, tiredness, a runny or blocked nose, sore throat, feeling nauseous, headache and dizziness. All of these side-effects were familiar to the respondents of this survey. The most common side-effects experienced were tiredness (53 per cent of respondents) and headache (39 per cent) (see figure 12).

Figure 12



Some 35 per cent of respondents who had taken Tysabri had sought medical help because of their side-effects (figure 13). This appears to be a lot lower than in self-injected DMDs where 60 per cent of respondents had sought medical help due to side-effects.

Figure 13



Worry about side effects

In addition to the side-effects listed above, taking Tysabri increases the risk of PML, a viral brain infection which can be fatal. In light of this, it is not completely surprising that over 40 per cent of respondents (figure 11) always worry about the side-effects:

> *"I now have very few new symptoms and have only had 2 relapses whilst taking this drug (Tysabri) - although I do worry about PML. As I expected, none of the drugs have improved my disability, but I feel at last that I have plateaued."*

although the fear of PML can be mitigated by being closely monitored:

> *"One of the nasty side effects of tysabri is PML but at least I am surrounded by doctors/nurses when I take drug and I am closely monitored as well."*

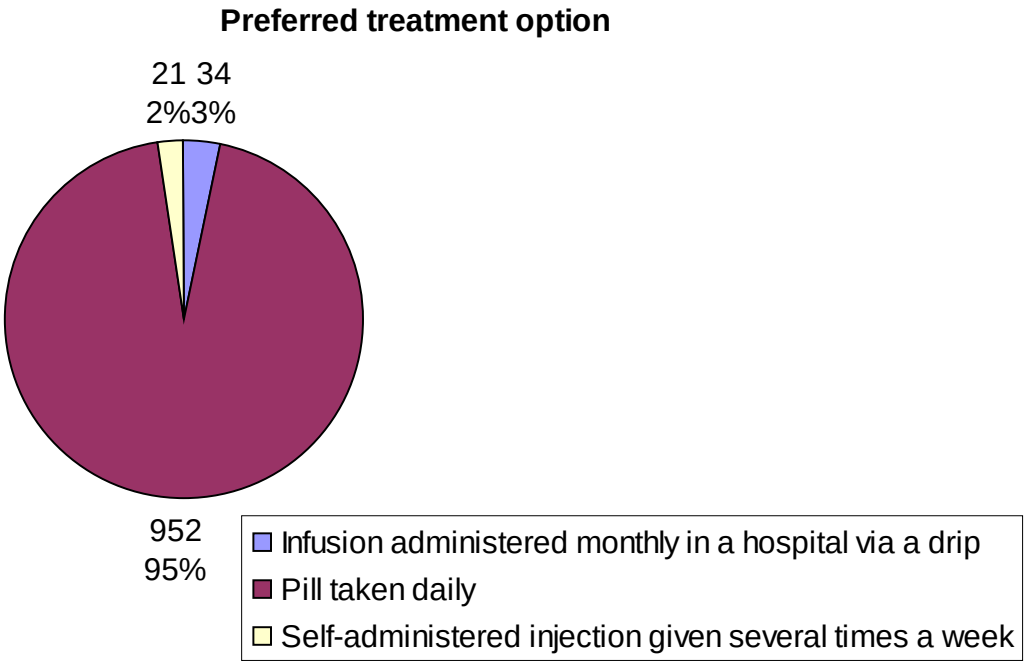
As already discussed, the risk of PML was also commonly given as a reason for discontinuing the treatment. However, despite this, the free comments relating to Tysabri told a very different, more positive story overall compared to those related to injected DMDs:

> *"I was diagnosed with rapidly evolving MS in Feb 2009. I started on Tysabri in March 2009 and I have not had a relapse since. I still have problems with my mobility and speech from my previous relapses but after 17 months of sickness absence from work I am finally stable enough to go back to work. That's all thanks to the Tysabri."*

4. Preferences for disease modifying therapies

The final question in the survey asked for respondents' preference for administering a disease modifying drug if three options were available: an infusion administered monthly in a hospital via a drip, self-administered injection given several times a week and a pill taken daily (see figure 14). Everyone who was qualified to take part in this survey was asked to answer this question, and the total number of responses was 1007.

Figure 14



The overwhelming majority (95 per cent) chose the pill option, giving ease of use, convenience to everyday life and non-invasiveness as reasons for selecting this option:

> *"Taking a tablet I could get on with my every day living, as I should be able to do even though I have MS."*
>
> *"I am trying to maintain a normal life and stay in employment. My work means that I sometimes need to be away from home. Having to inject at specific days/ times means my flexibility while I am away is much reduced. A drug administered orally would make working life much easier."*
>
> *"It would be the easiest and least obtrusive method, would fit in better with my lifestyle and would enable me to control my illness in a way which does not draw attention to my disability. It's bad enough living with the illness, coping with the symptoms and trying to get on with life without having to add to the stress with hospital visits and injections."*

Respondents to this survey have shown that the impact of MS is not only limited to people with MS but extends to their friends and family as well. Whilst helpful at times, treatments can also unnecessarily complicate lives and be a constant reminder of one's condition. Just like everyone else, respondents to this questionnaire want to live independently, stay in employment, take care of their families and go on holidays without having to plan, worry and deal with physical and emotional discomfort. It is vital that disease modifying drugs are effective, easy to use and fit around a person's every day life.

> *"If there was a high risk treatment which could potentially cure my MS I would seize the opportunity with both hands as I want to be normal again and not have to endure debilitating relapses several times a year, which set me back so far and mean I have rely on others to help me, when I just want to be able to do the things that everyone else takes for granted."*

Appendix C: Free text responses to an open question on experiences of relapses and/or disease modifying drugs

Perspectives of people with MS on disease modifying drugs

If you would like to tell us anything else about your experiences of relapses and/or taking disease modifying drugs you can use the space below.

Answer Options	Response Count
	421
answered question	**421**
skipped question	**709**

Number	Response Date	Response Text
1	Mar 25, 2010 12:11 PM	xxxxxxxxxxxxxxxx
2	Mar 26, 2010 9:15 AM	I feel I am at this moment in time expieriencing a relapse. It seems to be lasting longer than ever, I would be so grateful to receive tablets that would aid my recovery. I have suffered with MS for 20 years, I think I deserve a break.
3	Mar 26, 2010 9:27 AM	Since starting the DMD's I haven't had a relapse, but I am unsure whether the drugs are having an affect or it is just coincidence.
4	Mar 26, 2010 9:30 AM	I is painful when done in the same spot. My thighs are dented, red and scarred from injections. Relapses are awful and I have been taken to A&E by my family before and then had to have an hour long steroid drip everyday for three days.
5	Mar 26, 2010 9:34 AM	I would hope that any treatment for MS patients now or in the future is free as it is for other conditions.
6	Mar 26, 2010 9:37 AM	I have recovered well from my relapses, with small symtoms remaining. So I know I'm a great candidate for DMT. I havent relapsed since I've been on Rebif, so cannot comment if my relapses are less severe with it. My relapses have always reqiured hospitalisation, and I am lucky to have recovered quickly from them, although my last 2 relapses were very close and took longer to recover from. I am hopeful the DMT will prolong my remissions etc. I have been injecting Rebif via the Rebismart for a week, and am begining to understand all of my perameters with the drug - site reactions have caused some pain, redding, tenderness and flu-like side effects, which I am learning to manage - but evidently I'm only on 8mg now! So, how I react on more, remains to be seen. I find it frustrating that when I take the drug it governs what I do - I'm only in my early 30's and whilst I may not be able to stay out as long as I would like to any more, I would still like to be able to partake in all the activities, without thinking when I have to inject.....
7	Mar 26, 2010 9:41 AM	I have been left with red marks and dry skin where I have injected for several months after the treatment and my skin has not recovered fully yet.
8	Mar 26, 2010 10:31 AM	I am getting worse everyday,they say I have RRMS but I believe I have SPMS has my systoms are always the same everyday the pains are getting worse,feel like a spastic,can,t get my words out & finding hard to cope.I am a x-addict which I think stops them giving me meds for my ms,I,ve been put on Gabapentin but haven,t noticed much change yet! only started them a wk ago,got to slowly take them to take 3 a day.Had a infusion for 3 days didn,t help,don,t want to have them as being a x drug addict my veins are scared,took a while to find a vein.I am also on methadone,is this the reason I don,t get much help,I feel like I,m left to rott away with the ms.
9	Mar 26,	I found that while in a relapse my skin was very tough, I had a visit by a specialist

	2010 10:31 AM	nurse from the company who supplied my drug and she saw how difficult it was for me, she thought the needle may be blunt but after checking the batch they were perfectly fine it was just my skin was like the hide of a Rhino. I tried the injector pen but it was so sore and far to quick - it made a snap sound which I would try not to jump from but it was hard, I would bleed and bruise at the site of the injection from the pen, my legs (thighs) have become scarred from the injections - I stopped after giving them a good try, I felt that they were beneficial in helping my fatigue and memory but the side effects were as bad as the ms for me, my theory was why hurt myself more when I have a disease that can do that I'm just adding more pain and suffering to it. A pill would be like a God send!
	Mar 26, 2010 10:47 AM	I have been on Avonex for just over 4 years & I still suffer very bad side-effects after injecting. This includes flu like symptoms, joints aching, chest pains, breathing problems. This starts in the night after injecting & goes on for the next 3 days.
10	Mar 26, 2010 10:48 AM	I'm losing half my week ALL the time!!!!
11	Mar 26, 2010 10:56 AM	i am on my first relapse after being diagnosed four years ago. I have now been off work for 3 months and looking to start back in the next couple of weeks on reduced hours for a while.
12	Mar 26, 2010 11:05 AM	A s a nurse i feel for both myself and other sufferer's of RRMS i have to work with some people who have to suffer with the problems on a day to day basis. There is not enough support out there from professionals as much as i would like there to be. I am not needle phobic normally but since having to inject myself regularly i have hot flushes sickness feelings before injecting as i know i am going to hurt myself!!!
13	Mar 26, 2010 11:27 AM	I have told my neurologist on a regular basis that i would gladly take about 14 pills a day if they got rid of the injections, so anybody who does not agree with this, needs their head examined because if they had to do it then they would think twice!!!!!!!
14	Mar 26, 2010 11:35 AM	I was incredibly sick when having a relapse and it lasted a period of 5 weeks being off work - it has always left me a side effect i.e unable to use my right hand and leg as it has always had knock on effect, My balance has also been affected after a recent relapse. I do not enjoy taking the injections as I inject them intra muscularly and I feel so ill after I have taken it.
15	Mar 26, 2010 11:46 AM	I gives me hope anf the motivation to carry on .
16	Mar 26, 2010 11:56 AM	When I have relapsed I was given Dexamethasone
17	Mar 26, 2010 11:58 AM	Relapses are awful because just when you start to cope with how you are, a relapse comes along and knocks you for six, both mentally and physically. Some relapses make old disabilities reappear, or bring along new symptoms. The fear is always there, that you wont recover from this relapse or be left with a more permanent visable disability and then there is the relapse time and the additional recovery time on top. What is the point in these oral drugs getting trials if in the end, only certain people will get them, if NICE decide they can have them at all. It shouldnt be about money but what a person needs to have a decent life and if taking a pill everyday gives me that life, then i would take it.
18	Mar 26, 2010 12:01 PM	I have only been on Rebif 22 for 8 weeks and I am having problems with the side effects not sure how long I will continue with this treatment taking Rebif using the Rebismart device is simple and i would not consider anything else at present.
19		I have been offered DMD's by my consultant but due to the possible side effects and having to self inject I have so far resisted. If there was an oral alternative then I would seriously considered this option.

20	Mar 26, 2010 12:12 PM	My first relpase lasted for 6 months, sight loss paralysis etc, very frightening!! Couldn't to to work as needed help to live day to day and care for my 18 month old baby and 7 year old. Didn't know what was happening, however, now diagnosed my relpases haven't been as severe but still bad enough to prevent me carrying out normal activities and need to take time off work.
21	Mar 26, 2010 12:19 PM	I have found that any relapes I had while taking Avonex where much milder and shorter than before.
22	Mar 26, 2010 12:33 PM	im currently in the process of seeing my neurologist to receive the disease modifying drugs as i feel like some of my symptoms have worsened and i am now starting to experience new ones. Although I have not had a serious relapse I'm not sure if I have in fact suffered a relapse as I'm still trying to distinguish between a relapse and a symptom.
23	Mar 26, 2010 12:49 PM	I have always resisted DMDs due to potential side effects.
24	Mar 26, 2010 12:55 PM	I continued to have major flu-like symptoms throughout the 4 years on Avonex. In addition, the DMD was stopped because there was a concern it was causing more grief to my legs where I was constantly injecting. My legs have improved quite a lot since stopping, but I have had a relapse, which is the first for 4 and a half years. So in my opinion, the DMDs work, but if there could be a better method of having them (ie orally!) then that would be the best all round!
25	Mar 26, 2010 1:15 PM	I as would I am sure most MS patients (especially those on Interferons and similar) be extremely happy to take the new drugs (i.e. cladribine) as soon as possible as until we try these new medications we will not reach the ultimate aim of ridding the world of MS (or indeed managing its effects) Jason Dodds
26	Mar 26, 2010 1:19 PM	I've had RRMS for 8years now and have had frequent relapses with steroid infusions in and out of hospital. Rebif x3 weekly was an instant no no for me. side effects every night and skin reactions along with more disruption to my life. I administer avonex myself once weekly and don't find it a problem but still have occasional side effects. I've been offered Tsybari, but feel the risk of PML too high. I'm still walking and working, so i'll have to wait and see what else is offered.
27	Mar 26, 2010 1:20 PM	Why is there no research in the UK for CCVSI, I understand that this is very effective in America!
28	Mar 26, 2010 1:27 PM	Tysabri has been brilliantly effective and I am working full-time. Shame it took 5 and a half months of continually worsening symptoms to get the treatment after diagnosis. Shame I wasn't forewarned of how long the hospital visit would take (patients are told 1 hour infusion + 1 hour obs - first visit was 7.5 hours, subsequent ones never less than 4 - not a problem now I know to take packed lunch + work, but v annoying on first visit when I was unprepared)
29	Mar 26, 2010 2:41 PM	i just wish they would bring out a tablet to cure MS which would be good rather then injecting all week! the relapse i had last year was horrnedous as i did not know what was wrong with me!
30	Mar 26, 2010 3:00 PM	Injecting yourself every other day does become part of your routine but at times it's tricky if you're travelling and have to carry equipment/sharps bins etc with you.
31	Mar 26, 2010 3:14 PM	I have only recently started on Rebif - I feel a lot better for taking it (taking control) but it is a 3-weekly dread for me each time I remember I have to inject that day Easier to administer than injections No skin reactions ie; dimpled skin, sore/red rashes on skin, bruising, lumps under

		skin, pain, blood, unsightly skin on thighs, stomach, forearms, sides
32	Mar 26, 2010 3:14 PM	They should be available to people diagnosed with MS upon diagnosis.
33	Mar 26, 2010 3:21 PM	The only thing that gets me back on track after a serious relapse has been steroids.
34	Mar 26, 2010 3:32 PM	In the almost two years since I started on rebiff I have had one very minor relapse (which may have been stress rather than a relapse) but in the two years prior I had 3 serious relapses. In my opinion DMDs work. However injecting is often painfull and the bane of my life.
35	Mar 26, 2010 3:57 PM	I have had several experiences of being on a 3 day steroid drip to treat a relapse - I have preferred it when it has been possible to stay in overnight, rather than go back and forth to the hospital for 3 days. This is tiring when suffering a relapse and also makes me dependent on someone to get me to the hospital 3 days in a row.
36	Mar 26, 2010 3:58 PM	I must admit that I am fairly new to the DMD therapies so cannot offer much experience commentary however I know that a pill or liquid medicine to be taken orally would be much safer and more pleasant to take. I am not squeamish about injections but doing a jab myself every week does give me the jitters.
37	Mar 26, 2010 4:06 PM	rehelapses are less frequent now i am on dmd tho when they do occur they disrupt my life completely the last relapse i had lasted for a couple of mths.thats 2mths of bed rest and not being able to do anything for myself.this is really hard on my family.
38	Mar 26, 2010 4:12 PM	Please see comments on previous page. I feel all with MS who require these drugs are in effect guinea pigs and everyone should do their research and then make informed choices.
39	Mar 26, 2010 4:15 PM	Diagnosed with aggressive r/r MS, I was fortunate to be given Azathioprine at a time when disease-modifying drugs were not allowed. From being admitted to hospital around four times a year with long relapses, I never again suffered such a devastating relapse and did not and do not require in-hospital treatment any more.
40	Mar 26, 2010 4:29 PM	The DMD follow-up blood tests never take place. I get an annual check-up and that's the only time blood samples get taken!
41	Mar 26, 2010 4:49 PM	Too many side effects with Rebiff; switched to Copaxone but often find myself not injecting as I developped a mental block against the injection needle I have used Betaferon for 12 years now. It has nver got any easier to inject myself or any easier to ask my husband to do it for me. Indeed it can cause friction between us because we both get anxious so a tablet would be just wonderful it that respect. But an injection also often hurts and caused unsightly marks that never really dissappear Plus when going on holiday or away you always have to think about how you will cope with the injections - this will not be an issue with a tablet.
42	Mar 26, 2010 5:04 PM	Life would become so much more normal again
43	Mar 26, 2010 5:05 PM	I hear from others that regular injections are very uncomfortable. MS is an awful illness and everything must be done to make life more bearable.
44	Mar 26, 2010	After 12 months of taking a DMD I am a lot more accepting of the injections however I still have periods where I have injection site problems. I also find that if I will do

	5:10 PM	swim or other exercise these site marks are unsitely. Work wise, business travel is more of a concern when I have to manage a 3 times a week injection schedule.
45	Mar 26, 2010 5:10 PM	I hate needles which dosen't help. Avonex gave me a severe flu side affect which effectively romoved one day a week from my life while I took it. Copaxone still give me a rash.
46	Mar 26, 2010 5:14 PM	I know I am worse when not well, when overheated and when stressed
47	Mar 26, 2010 5:21 PM	i currently am lucky enough to be able to take Sativex. Unfortunately, it is still unlicensed and I do live with the possibility that it will never get licensed and may be taken away at some stage. It does me a lot of good and I would hate to see it go. I understand that it isn't a dmg as such, but it makes me feel better in myself in order for me to get out and about and keep fit and not be a burden on my family or society. i wish the government had more thought about prevention rather than cure with illnesses per se not just MS. If they could see that i currently lead an average kind of life, which is very good after 20 years, and that it may mean that I won't be a drain on resources later in life.
48	Mar 26, 2010 5:21 PM	Just not a pleasent experience. MS is bad enough without having to organise your life around your medication. Which in turn is not very pleasent and not very effective.
49	Mar 26, 2010 5:26 PM	Injecting just once a week disrupt your whole life and sometime it can be excruciating I take baclofen 3 x 10mg daily and I do not know how this is affecting me. I also take fesoterodine fumerate 2 x 4mg daily and this helps with bladder control.
50	Mar 26, 2010 5:30 PM	Although I was only diagnosed in August 2009 I think I have had this disease for at least 20 years.
51	Mar 26, 2010 5:40 PM	It is utter hell and there is no support if I want to carry on with a normal life. A relapse is so individual and unpredictable that it is impossible to get help without taking time off work for a long period and actively seeking help, which involves many different agencies and people. Even small disability help is hard when you're just able enough not to fufil the criteria. The most difficult thing I do every day is wash and get dressed, but because I can, I don't tick the right box for example.
52	Mar 26, 2010 5:53 PM	They just did not work for me - currently undergoing chemotherapy every 3 months, but appears to be having no effect - something for secondary progressive urgently needed
53	Mar 26, 2010 5:59 PM	It is a frightening thing being told that DMDs are only available via an injection and that you have to do it. To begin with, it controls your life as it is against human nature to hurt yourself and even more trickier when trying to inject with a tremor. It's not pleasant experiencing the flu-like symptoms, but I think this would be far easier to cope with if you didn't have to inject as well.
54	Mar 26, 2010 6:02 PM	i have been frustrated with rebif as I still relapse 3 or 4 times a year which causes a lot of disruptioon in my life, however since starting this drug I have not had the severe relapses i used to have which often involved a stay in hospital and me being very ill at home and unable to look after myself.
55	Mar 26, 2010 6:11 PM	Relapses are not only worrying, painful & distressing at the time but can take a considerable amount of time to recover from, I have been left with residual problems from every relapse I have had & then the worry of if I have another is the disease progressing quicker than I'd hoped, & that is always a worry at the back of my mind. I then worry about the impact on my husband & that he has to take time off work to help me. The concern that he will not cope if I become severely affected by another relapse is a genuine worry as he gets extremely frustrated with the whole MS

		scenario. As a very independant lady this adds it's own issues to my state of mind & the fact that I cannot be there as readily for my children & colleagues.
56	Mar 26, 2010 6:19 PM	My consutant thinks that the side efects would outweigh the benefits of the drugs at the moment, even though I'm having quite a few relapses, so won't prescribe any desease modifying drugs. I worry that the progression of thre disease would be better controlled if i was on the drugs tha as i am now.
57	Mar 26, 2010 6:19 PM	Betaferon was a big hope for me at the time - but I just COULDN'T inject myself. Ghastly. My relapsing/remitting is now secondary progressive. Sad.
58	Mar 26, 2010 6:25 PM	Only diagnosed 2.5 years and my decision not to take DMDs initially - hoping (unrealistically) relapses would not happen or if they did would not be as bad as original - the fact that oral medication was not an option definately figured in decision.
59	Mar 26, 2010 6:30 PM	Relapses are absolutely soul-destroying, so having to put up with a few flu-like symptoms is neither here nor there(especially as MS tends to make you feel awful most of the time anyway). Side effects like this are a small price to pay for the benefits these drugs can bring.
60	Mar 26, 2010 6:34 PM	Find a big problem having to remember when to take injections is a bit easier with new battery powered injector which store all info on machine
61	Mar 26, 2010 6:35 PM	It causes me a lot of pain and discomfort.
62	Mar 26, 2010 6:39 PM	Avonex gave me almost unacceptable side effects (totally out of action for 24 hours with MS type side effects). it helped reduce relapses but didn't eliminate them. Early days for tysabri. the main difficulty is the travel to hospital (but maybe i'll get used to that) and the time off work required for the treatment. but I remain hopeful.
63	Mar 26, 2010 6:39 PM	No MS related comments
64	Mar 26, 2010 6:47 PM	My experience of Copaxone has been life changing but I would still not choose to administer the drug in the form of injection. I have had so far only the initial expected relapse since injecting this drug.
65	Mar 26, 2010 6:51 PM	Relapses can make it difficult to plan ahead except in a tentative way.
66	Mar 26, 2010 6:55 PM	Usually feel quite ill especially head pains and pressure, aching, flu symptoms about 4 hrs after and may last a day and a half. It would make my life so much better to know that I would not have to inject each week as I dread it now that I get the pains when injecting. My eyesight is getting worse and that worries me with the injections too.
67	Mar 26, 2010 6:57 PM	Occasion ally I make a little buise, but keeping the relapsing down is worth it, and the stiffness and flu klike systoms
68	Mar 26, 2010 7:00 PM	I personally have found Copaxone to keep me almost true relapse free since I began taking it. My fatigue levels which were affecting my life before starting on Copaxone also seem to be improved in a great way, it was noticable from very early days of starting.
69	Mar 26, 2010 7:08 PM	I find injecting very painful and always get skin reactions - I now have lipoatrophy which is very unsightly but have no choice but to carry on because I do not want my MS to progress further.
70	Mar 26, 2010 7:09 PM	while on Rebif the flu like symptoms never changed, and that made life difficult as the flu like symptoms would last into the next day, so that would be three days lost out of a week
71	Mar 26, 2010	That I have received great care from my consultant

	7:11 PM Mar 26, 2010	
72	7:19 PM Mar 26, 2010	I like Tysabri (so far ...) and feel better than I have for years!
73	7:37 PM Mar 26, 2010	I initially thought when I started injecting I would not have so many relapses but in reality I sill get them although I tell myself I get less now. I hate injecting through a relapse because of the effort and the feeling of they are not working so why bother putting myself through the trauma. I have not missed an injection but it is more my willfull nature than what I want to do. I had to fight so hard to get on the drugs that whether they are working or not I am determined to take them.
74	7:44 PM Mar 26, 2010	ms consult
75	7:47 PM Mar 26, 2010	it's horrid having a relapse and not to be able to do things that in the past were easy, and done without thinking
76	7:50 PM Mar 26, 2010	I feel very thankful that I have injections and that they are helping, I hope
77	7:52 PM Mar 26, 2010	life is a struggle
78	7:53 PM Mar 26, 2010	Have never taken any.
79	7:53 PM Mar 26, 2010	The effects that the drugs were supposed to have on me - i.e weaker relapses and longer remission periods - appear to be happening in my case. My MS. is getting progressively worse but few if any noticeable relapses.
80	7:55 PM Mar 26, 2010	I have been on Copaxone for six months. I was havng a relapse every few months and I have had nothing since taking the drug. This might not sound too severe to some people but some of my relapses have affected my mobility and scared me. Copaxone has given me confidence that my relapses are slowing down. To have this, or indeed a pill, makes me think I will be able to work longer and hold MS off longer. I am 35 and have two children. These drugs are working for me and I would like it to stay that wa,y with me being able to get any drugs that I need. Surely, keeping me fit enough to work and live a 'normal' life is a benefit to the people paying for these drugs?
81	8:02 PM Mar 26, 2010	I work full time for the NHS as a band 7 Occupational therapist - to do this properly I have to lose all aspects of life - I can't clean my home , go out and sometimes cant even make myself a cup of tea as I am so exhausted. I try to limit the impact at work by taking annual leave instead of sick leave if I feel I am losing energy which means I spend alot of annual leave in bed recovering from work. I would fall into depression about the lack of life if I had not got such wonderful family, friends and colleagues.
82	8:09 PM Mar 26, 2010	Please work hard to source this, it will mean so much. Thank you as ever.
83	8:15 PM Mar 26, 2010	Relapses are scary never knowing how long they will last and how disabled I will be left after the relapse.
84	8:20 PM	as i said I would like to use the injection you take once a week I am a normal human being like everyone else who has this disease. I still work full time, pay my tax and national insurance. I never wanted to be a burden on the economy and still don't want to be. If I can get the best medication to help me and to help keep me well, to continue to contribute to the economy, then that can only be good. If I stay well, this should help reduce the impact on the economy - If I become unwell, not only will I need to stop working, but perhaps my carer / carers will need to reduce working hours and so claim Financial support from the govt, a further

		burden on the economy. The drugs are a means to an end - I don't want them but need them and so appreciate all the help I can get. Without medical support my last relapse may have had a worse effect on my body-it could have been more disabling. The side effect of the drugs are a blessing to me compared to the impacts on me without having them. I will persevere with whatever comes. During my last relapse, my head was so sore I could hardly see / eat - I felt so ill. I went to bed and hoped that I would not wake up. I have had MS for many years, but was only diagnosed almost 5 years ago aged 20 (after going private).
85	**Mar 26, 2010 8:24 PM**	I had to wait two years for access beta interferon treatment as it wasn't avilable for everyone in my province.
86	**Mar 26, 2010 8:52 PM**	In my experience (5 Years since dx) I had 3 obvious relapses in the first year. Since starting treatment on DMD I have only had 1 relapse on vision which commenced a few weeks before starting DMD. It has worsened over the last few years despite continueing with DMD. Other symptoms have slowly progressed or worsened over th last two years. I am still trying to work (Self Employed) but output is greatley reduced.
87	**Mar 26, 2010 8:59 PM**	DMD's have kept me mobile and working but the process of getting the drugs into the system is wrecking my body. Came off 2 treatments due to subcut. atrophy and when off treatment experienced a damaging relapse. Praying I will not get atrophy of muscle or I may be out of options.
88	**Mar 26, 2010 8:59 PM**	I would love to be on a drug with a greater efficacy so I can live my live, pay my mortgage and taxes and be happy.
89	**Mar 26, 2010 9:13 PM**	Not sure if DMDs are effective.
90	**Mar 26, 2010 9:18 PM**	Drugs for health conditions should improve your quality of life, not hamper it more. Injecting is horrible & I dread every other day.
91	**Mar 26, 2010 9:20 PM**	Since taking the drugs I have felt that the disease is being eased. Maintaining a regular exercise three or four times a week is helping me combat the balance issues, stamina and building strength in my overall body.
92	**Mar 26, 2010 9:34 PM**	drug woud be easier to tollerate, orally.
93	**Mar 26, 2010 9:37 PM**	I haven't really had any relapses since being on copaxone, other than minor flare up of symptoms after I've had a cold etc. Ive been injecting for 2 years. I am sometimes concerned about skin reactions and if these got worse then I would consider a pill provided there were no severe side effects.
94	**Mar 26, 2010 9:49 PM**	I find the day after my injection(im on betaferon) I get headaches.I also dont sleep well the night I have had the injection,and dont want to do much the next day,just stay in bed or watch tv. I had a major relapse in 2008,this is when I was diagnosed.which left me unable to work as I was a carer and always on my feet. Now I can only walk short distances. I started injecting in november 2008 after watching the betaferon dvd but I was disapointed as I didnt improve much.Ive been told that its just ment to slow down the progression but things have got worse quickly since ive been on betaferon.
95	**Mar 26, 2010 9:56 PM**	i have taken rebif, avonex and copaxone, side effects with each were different but just as disrupting to daily life.
96	**Mar 26, 2010**	My GP refused me Sativex.

	9:59 PM	I take bacolen - it does no good.
97	Mar 26, 2010 10:07 PM	I have had MS for 20 years and for the first 10 years it was relapsing/remitting. I have never been offered disease modifying drugs. I found relapses very frightening and upsetting, having to take time off work, deal with new symptoms, losing control of my life and independence. The uncertainty of not knowing what residual damage would be left when the relapse ended Relapses have been quite debilitating, affecting my ability, for instance, to get on with my work. However, I've not had any relapses since diagnosis, 6 months ago, so I'm not sure how I'd cope now that I know what it is, and have the support of an MS nurse.
98	Mar 26, 2010 10:12 PM	I feel like I've been lucky in terms of Rebif side effects, but an equally efficacious tablet would be easier to manage. I started taking Avonnex three years ago and had side effects at first that lasted 3-4 days every week for the first 3-4 months then 2 days for the next month. I really didnt want to continue to use this medication however my old Neurologist refused to allow me to stop. I felt that the side effects were taking over my life and I was ill for half the week and mostly bed bound. When the side effects lessened, it became bearable though it had had a dreadful effect on my working life and home life. I felt totally out of control of my life and not listened to by those who were supposed to care and support my decease and my health.
99	Mar 26, 2010 10:29 PM	Now thing are better and I only have 1 day of feeling unwell. I now have Secondary Progressive MS.
100	Mar 26, 2010 10:33 PM	They need to be more effective and less of a burden on daily life
101	Mar 26, 2010 10:41 PM	I used to inject Rebif 3 time a week but had so many reactions to the drug. It seemed to react with other foodstuffs like Chinese, Indian takeaway food. I went out for my best friends stag night had a few too many drinks but was fine when I went to bed. When I woke I was unable to walk. This had never happened before Rebif.
102	Mar 26, 2010 11:45 PM	I do not have relapses
103	Mar 26, 2010 11:47 PM	I had a course of Mitoxantrone over a number of years and then my treatment was transferred to Copaxone. This regime has worked well for me and I am very pleased about that.
104	Mar 26, 2010 11:56 PM	The actual act of injecting , fills me with dread, even though it has now been 18 months since I started.I have been phsically sick the day before and the day after injecting. An alternative, oral drug, would give me back 7 days a week, instead of 5.
105	Mar 27, 2010 12:08 AM	having the start of a second relapse within two years of last one and obviously you worry how much more damage is being done scarring wise. sounds as if there are so many more now on the market.
106	Mar 27, 2010 12:12 AM	I feel fortunate to have been on Avonex at all, I have no idea what my condition would be without it.
107	Mar 27, 2010 12:12 AM	I am one of the lucky ones who is on Betaferon as before I started this medication when I had a relapse I ended up in a wheelchair. Now touch wood when I have a relapse they are not as bad. People need to stop moaning and be thankful if they are getting the treatments they need whether injections or tablets. Life is too short some people are not so lucky.
108	Mar 27, 2010 12:31 AM	HAVING TO INJECT 3 TIMES A WEEK MEANT MS WAS CONSUMING MY LIFE AND I TOTALLY WAS AGAINST THIS .IT MADE ME PERCEIVE MYSELF AS BEING ILL WHEN I WASN'T .HAVING TO GET TRAVEL LETTERS .

109	Mar 27, 2010 1:05 AM	they tell you that you will experience flu like symptoms for about the first 6 months i have been on rebif for four years now and i still get the flu like symptoms so constantly have to take painkillers 3 times a week when i do my injections Q3 -none of the answers available were relevant but I have had to called NHS Direct when I had a particularly severe reaction. I have also discussed the reactions with the Copaxoen helpline and with my Specialist MS Nurse and consultant at routine appointments. Being able to take pills on flights would not be so intrusive as having to take injections and letters from the hospital to allow me to carry needles on the plane - one airport official asked what I felt was unecessarily intrusive questions.
110	Mar 27, 2010 7:14 AM	My relapses are now irregular but life affecting when they happen -usually affecting my legs. My determination to not make me stop my usual responsibilities -even when I perhgaps should -means some of my responses are 'occasionally' when they should be 'often' but I refuse to give in. Life with MS is a battle.
111	Mar 27, 2010 8:57 AM	Decided not to take disease-modifying drugs because I hated the thought of injecting myself on a regular basis. I'm scared to travel abroad with needles
112	Mar 27, 2010 10:10 AM	I find injecting difficult & most times painful I take diease modifying drugs because its the only option I have had steriods, firstly in tablet form which worked very well and stopped my relapse speedily
113	Mar 27, 2010 10:18 AM	secondly I had a three day intravenous course of steroids, this just make me feel worse.
114	Mar 27, 2010 10:24 AM	I have had 5 relapses in the last 6 months each getting worse and leaving me with more spastistity each time. Can't take too many steriods as I have osteoporosis. Have already had 5 courses in the last 6 months and this relapse Gabapentin has been increased to help with the pain. Avonex was taken every Friday night which meant anxiety all day beforehand, then forced myself to do it and then 'lost' the entire weekend (mainly in bed) due to the side effects
115	Mar 27, 2010 10:28 AM	In the end, I abandoned the treatment as it was worse than the disease
116	Mar 27, 2010 10:34 AM	I have recently started taking Amantadine, and am very pleased with the result so far.
117	Mar 27, 2010 10:50 AM	I have always got on with things with the help of my GP as I was told I do not have enough relapses to warrant medication.
118	Mar 27, 2010 10:54 AM	Because Rebif has to be kept refrigerated transportation eg going on holiday is very difficult. Making sure it is kept at the correct temperature on the plane and in the hotel while still having access is a problem.
119	Mar 27, 2010 10:56 AM	When having a relapse if it is bad I have had to take steroids , which do then mean that I am unable to function normally until the steroids wear off. I hated having to be injected with beta interferon and used to get very distressed and hate the day knowing an injection was coming.

		Tysabri has changed that for me as my relapses have reduced and it is a relief to have only;y one infusion every 4 weeks rather than 3 injections a week.
120	Mar 27, 2010 11:45 AM	The injections make me ill and although there was a slight reduction in relapses, the side effects of the drugs made day to day living very tough.
121	Mar 27, 2010 12:00 PM	Obviously you get more proficient with the injections as time goes on, but it is fiddly and trying to remove air bubbles can be difficult. I have had the syringe/ needle fall apart in the auto-injector once because the needle assembly had worked loose.
122	Mar 27, 2010 12:06 PM	i would appreciate a drug or something that would keep me at the position I am now. I feel if maybe I had been given something earlier I would not be as bad as I am now.
123	Mar 27, 2010 12:27 PM	I am currently on Rebif and have not had a relapse since I started treatment - nearly a year now, so the treatment seems to be working well for me, so I'm happy about that. I just hate the injections, so if I was able to change to pills and they would work as well as the Rebif, then I'd be over the moon!
124	Mar 27, 2010 12:39 PM	I have experienced bad relapses and been in hospital. I don't want my MS getting any worse. I have had relapse attacks but they have got better in a few days and my MS Nurse has given my husband and mother advice.
125	Mar 27, 2010 12:56 PM	I do not wish to take a drug that does not have a positive effect, I feel that the arrangement with Avonex is very successful and has kept me working and living as normally as I can at present. I would not take a drug that had serious, permanent side effects. Although if it was a definate cure I would take the chance!
126	Mar 27, 2010 12:59 PM	I currently take DMD, and may move from Betaferon to Tysabri as I have suffered with a new relapses since starting Betaferon as suggested by my Consultant
127	Mar 27, 2010 2:03 PM	I have had very few relapses since being on the injections. However, it is hard to know if this is because of the injections or because I have gone into secondary progressive MS.
128	Mar 27, 2010 2:15 PM	I WOULD DEARLY LOVE A CHANGE TO TABLET FORM AS DESCRIBED PREVIOUSLY.
129	Mar 27, 2010 2:37 PM	I started on rebif 22 after a big relapse which left me sightless for a few months. The rebif treatment was going very well, and I experienced no further major relapses whilst on it, only slight niggles such as tingly fingers, wobbly leg and slight vision issues The formulation of the rebif changed early last year, and after a few months of being on that, I started getting back ache, which worstened when moving up to 44 in september. At the same time I moved from the rebiject to the rebismart. The site reactions were supposed to be a lot less, but I found them even worse. I also got stomach/constipation issues, which got so bad and constant that I was taken off the injections. I still have the stomach aches but to a lesser degree (only stopped rebif in february) and hopefully they will be better in a few months when the rebif is fully out of the system. I do worry though what comes next. I have been advised that tysabri might be good - but the thought of possibly taking tablets instead gives me hope.
130	Mar 27, 2010 2:40 PM	Rebif provided no change in the pattern, frequency or severity of relapses. I had approximately four relapses in the 18 months I took it, which was the same number of replases I had when not on any DMD. I have been taking Copaxone for over two and a half years and have not had an acute relapse in that time.
131	Mar 27, 2010 2:45 PM	Relapses are a nightmare, particularly as they are so unpredictable. I know that employers are deeply sceptical about employing someone with RRMS, and frankly I don't blame them. Who wants an employee who could get sick at any time, and who could be off for months with a potentially reduced ability upon their return. I still work but while I think the DMD may have initially helped with reduction of relapses, they

		may not have done and certainly aren't now. I find the injection a horrifying experience, I get cold, sweaty and shaky - this is before I inject! I think it is called terror! I hate the injection itself; it is painful. I don't like the horrible bruising and marks all over me. Even if I thought the DMDs were doing me the world of good I would still resent the injections and hate injecting myself and the side effects. Now that I am no longer convinced that the DMDs are doing anything of benefit, I am strongly tempted to stop altogether, but in the absence of any alternative, this is a drastic step to take and one I am afraid to take. My experience of relapses mean that I struggle to cope each day during one as I have to constantly consider the impact of the disease modifying drug on my insulin as the control of my diabetes is significantly affected during a relapse. An illustration of this is that once when I went hypo - as my insulin had become out of control due to the MS relapse- I was in the house on my own and I totally lost the use of my legs. I managed to drag myself on the floor from the lounge to the kitchen but I was unable to pull myself up to reach any food - luckily I was able to get a chocolate biscuit from my briefcase. I also once went to the toilet and then my legs collapsed and I was
132	**Mar 27, 2010 3:37 PM**	unable to stand up. I had not been hypo but I became so due to the stress caused as I could not open the toilet door either; luckily, on this occasion, my husband heard me and was able to help.
133	**Mar 27, 2010 3:47 PM**	I feel although I don't particularly like the injections, they are not really a problem and currently I have been a year without a relapse! First time since being diagnosed 6 years ago! So because of that I'm more than happy with taking the injection.
134	**Mar 27, 2010 4:10 PM**	I have never found a problem with taklng daily injections of copaxone and have travelled often abroad with no problems.
135	**Mar 27, 2010 4:11 PM**	I constantly suffer from chronic fatigue
136	**Mar 27, 2010 4:19 PM**	It is impossible to say how beneficial they have been to me personally which I find difficult. I would like to feel that it was definitely worth the tender blotches , muscle pain etc
137	**Mar 27, 2010 4:25 PM**	Since starting Rebif I have experienced a lot of nasty side-effects including unpleasant site reactions that last for weeks. From the research I've done the DMD's don't seem to have a great effect on either reducing relapses or disease progression in the long-term, so I often wonder why I'm putting myself through it all!!
138	**Mar 27, 2010 4:28 PM**	To date I have resisted taking medication as I have been fortunate enough not to have prolonged relapses. However, were my situation to worsen I would rather taken oral medication than any other form.
139	**Mar 27, 2010 5:01 PM**	Self injecting has become routine now after 9 years and seems to be working well for me.
140	**Mar 27, 2010 5:48 PM**	I have been on the drugs trial for Fingolimod for over three years now, and on the whole I have been quite "well". I feel I am doing something positive against this disease, as when I was offered DMD's originally it just filled me full of dread the thought of either me or a loved one having to inject me regularly.
141	**Mar 27, 2010 6:01 PM**	I am fortunate that I havent had to take drugs as yet but I do know that relapses make me feel awful and debilitated and it is very hard to explain to you family why you feel like you do.
142	**Mar 27, 2010 6:07 PM**	When experiencing a relapse this has an impact on my whole life and that of those closest to me. There is always the underlying fear/concern that a relapse may occur and how or whether this will affect my level of functioning and deterioration in the long term if recovery is not complete.

Taking disease modifying treatment has now become part of my routine, though there has been the rare occassion I have just considered maybe discontinuing the treatment as I am unsure whether there is an overall benefit and wheher the experience of the itchiness and soreness is worth it. However those are the days when I feel particularly sorry for myself!
Dear MS Group,

I have Multiple Scleros MS + Trigeminal Neuralgia TN. There is also a TN website

Currently take Amytriptiline and Tegratol Retard to try to control the pain. Please forgive me for any spelling errors.

Apart From trying to monitor my Jaw pains right hand side.

I have problems with my balance. I also wear a splint on my right leg. MS Currently use a walker to get about. I try to rely on this rather than use a wheelchair while I am able.

I try to regulate the tablets which I take for TN. I feel that the tablets I take can and do upset the usage of my leg/balance. Whilst I have cut down. Currently seem to have more usage in my right leg. I can still bend my right knee though it is rather stiff and hard going. My right ankle hardly works at all and the splint helps the right foot from dropping.

I hope that I am able to/allowed to use the recently develeoped tablets. Also if I am allowed to, my symptoms do not get worse. Hopefully my condition will improve.

Thank you for reading my email.

I am not very good at using/getting on to this computer.

Best wishes to all sufferers. Also I hope that there will be further scientific develeopments, and that we can be optimistic for the future.

Yours faithfully,

143 **Mar 27, 2010 6:16 PM** AEDMUSCODE

144	Mar 27, 2010 6:39 PM	Mrs. A. E. P. Edwards. I have only had very slight side effects from the medication and that was at the early stages of taking it.
145	Mar 27, 2010 6:58 PM	The flu like symptoms I get from avonex does alter what I do on the day I take it and the following day I also experience a relapse every couple of years. Compared to some people Im lucky but if there was another safe drug to take that was more effective and had less side effects that would be great.
146	Mar 27, 2010 7:32 PM	no info on coming off effects. and fear of not getting back on the scheme because of the cost.
147	Mar 27, 2010 7:34 PM	loss of vision in a relapse. Mix up getting delivery of copaxone. Fab service from connextion team (Copaxone) always call me to see how things are going and if I need anything or just want to talk about the treatment. Good experience with Mitoxantrone in stabaising my MS. I hate injecting and hate having to get my husband to inject me too
148	Mar 27, 2010 8:11 PM	Relapses change your life completely - not the same person at all any more. DMD are difficult to handle at time because of the bad side effects (not each week but for me I would say 3/5 weeks are a problem to me and I have had to live my life around this which is sometimes difficult, not only for me but my family too.
149	Mar 27, 2010 8:14 PM	The drug I was on did reduce my relapses - a third of 4 or 5 per year was/is worth all the bother of injections. Life is much better than it was. Before being on my first drug I had in one year - double vision, then one leg not working as it should, then falling/tripping due to feet having strange feelings and not going where they should, then half face becoming numb and scratching eye leading to problems in eye .... I felt that MS was really taking over my life. My first course of injections I felt was really working and I was very unhappy when MS Nurse told me to stop injecting as my blood was being affected. I had no idea what was happening to my blood, but I felt the drug was really helping to reduce the relapses. When I met with my consultant I told her I was very disappointed as it been the first time I had anything to help my MS. She Has now put me on another drug - still injecting.
150	Mar 27, 2010 9:32 PM	My initial response, when I heard these new tablet form drugs were to become available and I immediately contacted my MS nurse, to ask if I would become eligible when the drugs became available. She could not guarantee that I would be give these....but I am hopeful...
151	Mar 27,	Relapses really suck!!

	2010 10:19 PM	
152	Mar 28, 2010 3:50 AM	My symptoms and relapses have been relatively mild to date, but I they are becoming more frequent and severe, but so far I have manged not to take any drugs. My neurologist offereed beta-antiferon, but we agreed that this stage it was not necessary. My symptoms consist of permanent numbness/pins & needles in my right arm and over the last week a feeling like I have a 10kg weight strapped to my legs. This is the third time I have experienced the "heavy" legs. First time I took a short course of steroids, but the second time I let it run its course.
153	Mar 28, 2010 9:14 AM	I tried Rebif for a short while, but did not stay on it long enough to feel any benefit as it hurt too much. I then went onto Copaxone, which worked fantastic and enabled me to walk properly again, but I could not carry on with it, because the longer I used it the worse the pain got, which was causing me to be very anxious. It was making taking the drug by injection truly impossible. I was gutted.
154	Mar 28, 2010 9:48 AM	preparing people to manage the usual side effects of Bet Interferon= fever and importance of injection site rotation is key to them starting off well and continuing on their meds - the MS Specialist Nurse is key to this preparation.
155	Mar 28, 2010 10:13 AM	With the new pills I am concernned that people may assume that a pill is easily popped but not appreciate that these are heavyweight compounds which may have nasty side effects and that close monitoring bloods etc will need to be in place for their safe use.
156	Mar 28, 2010 11:41 AM	Injections are not a long term solution - there are only so many sites a body can put up with and after 3 years of daily injections, I have discussed with my MS nurse whether to give up the treatment for this reason. She persuaded me to keep going as the treatment (Copaxone) seems to help but I don't feel I can keep doing this much longer. I tried Avonex prior to Copaxone but had bad reactions in terms of flu symptoms & depression, so cannot try an Interferon based treatment again even if it does mean fewer injections.
157	Mar 28, 2010 11:53 AM	Since I have been taking Rebif (6 months), I have not had any relapses, whereas before starting the treatment I had several relapses one after the other.
158	Mar 28, 2010 11:59 AM	they help My relapses are mainly sensory so do not affect my ability to go about my day to day living greatly. Due to the change in feeling in my legs I no longer felt safe to work in my original job role when diagnosed therefore left for an office job. This lead to an episode of anxiety and mild depression which still bothers me from time to time. I have no problem injecting 3 times a week. I learnt to inject other people for my role some time before I started on interferon so easily moved to self injecting without any auto injector. It does involve planning when going on holiday as a fridge is needed in hotter climates, airlines need to be notified and delivery company contacted. I experience pain when injecting into my thighs and get skin reactions. More recently I have experienced flu like symptoms bad enough to require a day off work.
159	Mar 28, 2010 12:30 PM	It seems that a pill, like any other pill would make life easier in terms of the practicalities of a medication and would be easier to take regularly without any trepidation and pain. The thought of self-administering a drug by injection was, initially, very scary. This was also at a time when I was recovering from a disabling relapse and was very worried about my future so it was an extra worry I could have done without.

160	Mar 28, 2010 1:38 PM	I feel I have benefited greatly from the drug Rebif 44 mg over the past nearly 7 years. Relapses have not ceased but they are less severe and disabling than in earlier times (my MS was diagnosed in 1982 and has been a constant factor affecting my work and life over the years. I do not feel that strongly about the pill option but if i had to inject daily rather than 3x a wk then I certainly would!
161	Mar 28, 2010 1:44 PM	I would welcome any drugs that could be prescribed. I have had 4 bad relapses in the last 14 months causing me to have to take 6 months off work in total. I have now been made redundant and wonder if it was because of the disability? Anything to make life easier would be very beneficial to me and my family & friends.
162	Mar 28, 2010 1:51 PM	I even had some hypnosis sessions once to try to overcome the fear that I felt leading upto my weekly injection. Worked for a while but eventually the effect waned. I also have to work myself up to it, since giving yourself an injection deep into your muscle can be parelled with stabbing yourself. Not a natural human action to do 'damage' to yourself. I can be very down around injection time which you cannot necessarily share with others.
163	Mar 28, 2010 2:58 PM	I was diagnosed in 1998 with relapsing remitting ms, which proved to be very aggressive; I used to have about 10 severe relapses a year before I began my Rebif treatment. Unfortunately for me an awful lot of nerve damage occurred during those initial first years, resulting in me becoming very disabled, very quickly, leading to my early retirement. I have always had side effects; they are sometimes mild, sometimes awful! My ability is always diminished the following day after an injection, I have to take ibuprofen or paracetamol to counteract the worst of it! Rebif has definately slowed down my relapse rate, and my relapses are a fraction of the severity that they used to be. I really hope that a less bothersome treatment becomes available very soon...
164	Mar 28, 2010 4:06 PM	my relapses have been frequent un warned and has affected my ability to function independently and has had severe impact on my ability to work. I am currently unable to feel the right side of my body and cannot use my writing right hand and i am relying on the use of my left hand which i had lost sensation last year. I am also unable to lift my right leg nor move my toes so mobility is poor. I am wholly reliant on my partner to function within my home and the thought of a new drug which would reduce the relapses would be greatly welcomed I was meant to start rebif injection a couple of months ago however a suffered a rare blood clot in my brain which has led me needing to take warfarrin daily which rebif will interact with and injections will be more problemayic
165	Mar 28, 2010 4:19 PM	My relapses became more severe and more frequent after taking Avonex for 9 months. I continued to take it for a further 12 months but the side efects were interferring with my daily life and I couldn't see the benefit in aking it any longer. I lost faith in these dmds and now take nothing but Gabapentin for the pain and a vitamin D supplement.

166	Mar 28, 2010 4:21 PM	i was on copaxone first and had side effects like painful breast which i had for 4 months and several other side effects but then it was causing skin damage that was 18 months that i was on that injection, i have been on Avenex for just over 2 years but from the first day i started taking them i have a bad bad headache right after i have had my injection which lasts for about 4 days then i'm ok for 2 but then it's time again for it again i had night sweats and feeling cold, flu type syptoms, bad hallucinations, difficult sleeping. bad muscle cramps, pains in legs there have been many side effects from both of the injections which were not very pleasant at all. There is also the hassle of keeping the drug in the fridge (away from the children). There is all the paraphinalia with the equipment needed. Sharps box, auto injecter. Having to think about taking it all on holiday. Will there be a fridge to keep the Rebif in? A place to store it at home. Being in when the delivery van comes every month.
167	Mar 28, 2010 4:47 PM	Taking a tablet would be so much more convenient.
168	Mar 28, 2010 5:41 PM	I feel well on Copaxone and have not had a relapse since taking it but it is gradually ruining the areas where injected by leaving a permanent cellulite effect and there is less fat left to use for future injections so I can't view it as a long term treatment in the future
169	Mar 28, 2010 5:55 PM	When I was originally diagnosed in 1976, I was injecting every day with ACTH. The experience I had with that has put me off injecting myself for ever!!!!
170	Mar 28, 2010 6:07 PM	Disease modifying drugs have allowed me to keep working (along with sheer bloody determination). Injecting myself is a skill I have learnt and side effects are small price for me to pay. I do worry that having developed a resistance to Avonex the same will happen with Beta-feron.
171	Mar 28, 2010 7:02 PM	G.Ps could be better informed and take things a little more seriously than your usual 4 minute appointment allows.
172	Mar 28, 2010 7:07 PM	i have been fortunate to have been given the drug Campath for my acute MS. I used to suffer from very bad relapses at least one big attack every few months most of them leaving me unable to walk for weeks on end. Just when I had started to recover from one bad attack and it was normally the beginning of yet another relapse. Since taking Campath in 2007 I have had a new lease of life, and havent experienced a bad relapse since August 2007. I still have residual symptoms and sometimes I suffer from very minor relapses, normally only lasting between 24 and 48 hours but nothing as bad as I used to get in the past.
173	Mar 28, 2010 7:28 PM	Access to the latest Drugs and the continuation of effective research is vital for all us MS suffferers as it provides us with options and for hope.
174	Mar 28, 2010 8:24 PM	i know it is not a cure but i will try anything that might help, and that i might be able to feel normal
175	Mar 28, 2010 8:24 PM	I hate injection night even after all these years..... and the 24 hours after!!
176	Mar 29, 2010 7:15 AM	Regular appointments to discuss the drug and monitor for side effects was reassuring.
177	Mar 29, 2010 8:27 AM	Whilst injecting is fairly straightforward, it can be quite uncomfortable and taking a tablet daily would be so much easier and simpler. Before I was put on Copaxone I had several major relapse that had left me compleatly paralysed in both arms and legs, unable to talk or eat normal food and severe double vision. The last major relase kept me in hospital for three months. I also had a DVT while in hospital because of lack of movement in my limbs. Since

178	Mar 29, 2010 8:39 AM	being on this drug I have had minor ups and downs but nothing to hospitalise me. I take Avonex on a weekly basis, and although my relapses feels under control I feel that I have to give up a day every week to deal with the side effects of Avonex, this is invariably at the weekend which means I have to give up 24hrs of my free time each week to dealing with the side effects. In addition the injecting process can be quite a strain mentally. People don,t realise how debilitating this desease is, and in a lot of cases can,t be seen on the outside.
179	Mar 29, 2010 9:03 AM	The treatments I have had over the last thirty years have been Steroids, Tegretol and now I'm taking Gabapentin and Destrusitol for my bladder. I have relapsing remitting MS although it's been more relapsing in the last 12 months. Initially the injections are scary, they are painful & leave your skin bruised. Going on holiday is a nusiance getting your medication through the airport, all your equipment has to be searched!!!
180	Mar 29, 2010 9:23 AM	A pill would be amazing, please, please hurry
181	Mar 29, 2010 9:46 AM	A relapse must be the most frightening thing to happen in one's life. You never know how long its going to last and what effect it is going to have on you and all the people around you. When you are no longer in control of your body/mind you feel so lonely, dpressed and vulnerable.
182	Mar 29, 2010 10:39 AM	I didnt realise how bad the rebif injections were making me feel until I stopped taking them. I am unsure if they assisted with decreasing relapses as I wasnt on them for very long due to the reactions andmy relapses are not hugely frequent although obviously I met the criteria for the treatment
183	Mar 29, 2010 10:49 AM	I am hypersensitive to medication side effects, so although, I believe that being on DMTs has reduced my number of relapses over the years, I have at times been unable to manage the side effects and have had to come off interferron completely. Now that I'm on Copaxone I feel well, but have a lot of pain after the injection and I worry a lot about eventual lipoatrophy. I am eager for a DMT in the form of a tablet to be approved, though I worry that I would not be able to take it because of its side effects.
184	Mar 29, 2010 10:50 AM	My relapses make me feel suicidal. Fortunately, I have a child and he makes giving up an impossibility. Any chance of having a drug that would ease some of my everyday difficulties and one that I could easily administer in a pill form is my one big hope. It would give me a future to look forward to. Once or twice I have been able to have a short course of steroids to clear up some symptoms of a relapse, but I am not keen to take them too often.
185	Mar 29, 2010 11:07 AM	I do not have many relapses and for the most part I am fit and well and able to carry on with a normal life with no problems. I feel that Rebif is helping and if I was not taking it I could be having more relapses. Relapses are a constant reminder of the progression of the disease. You are always aware that you will be less able after one and that it is a progressive disease.
186	Mar 29, 2010 11:16 AM	Injecting medication requires a lot of planning ,particularly when going on holiday.Access to fridges for storage isn't always available. You are also at the risk of syriges or injectors not working as they should.
187	Mar 29, 2010	i don't know if it is because of taking the rebif or just luck, but no significant relapses since taking it.

	11:26 AM	I felt extremely nervous and frightened when first told I would need to take the drugs - I became depressed at this time as the enormity of my diagnosis hit home, that this was it for life until the drugs stopped working. I think that if I was told that I could take a pill, it would have made life easier and less daunting, rather than having to decide how many times a week I wanted to be injected.
		With the Rebif (3 times a week) injections I had to plan my week to fit them in, it's easy to say it only takes 5 minutes to do the injection, at times it would take up to 30 mins to calm myself down enough to have the injections.
188	Mar 29, 2010 11:27 AM	Travelling is made more stressful as you have to ensure that 1) you can take the drugs with you on teh plane etc. and b) that your accomodation is suitable for storing the drugs. Also, you then have to plan your holiday around the injection.
189	Mar 29, 2010 11:47 AM	Relapses are an intrusion to normal life and the drugs are only partly effective. Sometimes the side effects are worse than the relapse symptoms. Medication needs to be effective and unintrusive, medication that can be self-adminstered at home gives greater independance to the patient.
190	Mar 29, 2010 12:10 PM	I have been taking Rebif now since the year after diagnosis, it however has never been a problem to me, my family have always said they wouldnt be able to inject me, so with the new oral medication, it seems more suitable for me and my family. I am thinking of my family in the long term, and the oral medication is more suited to them, I am however fearful that they do not work as effectively as the Rebif, but for my family I want/wish to change to the pill form as soon as possible.
191	Mar 29, 2010 12:17 PM	I suffered Post-natal depression which stemmed from my absolute fear of having a relapse and not being able to look after my daughter. This was coupled with anxiety attacks caused by fear of not getting enough sleep, becoming run down and then having a relapse. This desperately impacted my first 8 weeks after birth, which I'll never get back (was my first child). I haven't taken any steps for drugs as yet because injections seem so drastic and to be honest scares me.
192	Mar 29, 2010 12:25 PM	Take avonex - still have cold/flu like symptoms almost 3 years on since starting treatment. Tried Copaxone instead, but only lasted a week as the skin site reactions were awful. Lump like size of an egg, must have had an allergy to the ingredients. so went back on Avonex, trying to live with the side effects again as not other drugs at this time. However, had no relapses while on Avonex (could be coincidence but cannot be proven either way)
		I have relapsing remitting MS at present, but I feel that I am getting worse generally. I am to see a neurologist this week, and have been led to believe (by my MS nurse) that he will suggest a self-injected drug.
193	Mar 29, 2010 12:33 PM	I don't want to face it.
194	Mar 29, 2010 1:03 PM	I haven't had many relapses and disease hasn't really progressed - since taking Betaferon
195	Mar 29, 2010 1:42 PM	It becomes increasingly difficult to identify what is a relapse, (due to progression) and therefore monitoring the effectiveness of a taken medication is difficult/impossible.
196	Mar 29, 2010 1:55 PM	Rebif can only reduce th number of relapses. I have had a few relapses during the past two years. One, I'm convinced, brought on by stress in the work place, 25 years in the NHS. One brought on by a very heavy cold and now I'm told that my medication is under threat as I'm unable to walk 100m. unaided. I wish! So I'm

		feeling a little low at the moment and fighting my way through my current relapse. Since being on Rebif I've not suffered the dreadful fatigue that used to be my lot
197	Mar 29, 2010 2:26 PM	Travel with syringes, esp airports and flying, often difficult. Intramuscular injection is tiresome.
198	Mar 29, 2010 2:28 PM	I feel generally frustrated with there being so much said about MS but so little apparent recorded facts of the illness throughout the country where comparisons can be made and steps or lack of them justified.
199	Mar 29, 2010 2:47 PM	Weekly intramuscular injections are unpleasant. I imagine daily injections would be equally unnerving. The whole process is fairly hard to do when it is not actually making you feel better afterwards (generally worse for 24hrs), just slowing down the process of getting worse. If you have a head ache you take a pain killer and you feel better an hour later. Disease modifying drugs don't make you feel better or improve you, they just help your prognosis long term.
200	Mar 29, 2010 2:56 PM	I hated taking Betaferon - every other day the injection loomed and reminded me that I have MS. It was so painful! My bottom ended up covered in red wheels, puckered, with deep dips and very sore. The fat displacement is also unattractive. I still have these deep, irregular, subcutaneous pits and they are sensitive to sit on, 5 years after I stopped injecting the drug!
201	Mar 29, 2010 3:01 PM	The benifits of the Capaxone to my MS have been wonderful. It was difficult injecting every day but I am used to it now and only need help to inject where I can not reach. The only problem was going on holiday and keeping our fridge cool enough in our caravan while we were travelling. Hopefully this will be sorted out this year. I have not had the courage to fly with my needles etc as I dont feel confident taking every thing with me and having to keep the temperature correct for the Capaxone. Also having to explain everything to customs is a cause of concern.
202	Mar 29, 2010 3:05 PM	I am just using 22mg and yet I have a my high liver Enzyme is slightly high. I was advice by my doctor to keep injective beta interferon rebif
203	Mar 29, 2010 3:41 PM	I personally have serious side effects from taking rebif (peripheral neropathy, severe, headaches, worsening of raynauds diseas) I felt I was not taken off rebif early enough despite my reports to my MS nuses on my 3 monthly checks of the symptoms I was experiencing listed above. I was on rebif for 8 years. Unfortunately despite comming off rebif 12 months ago the side effects from this drug have left permenant damage. In my view the monioring of this drug treatment was inefficient.
204	Mar 29, 2010 3:47 PM	I felt my relapses were sometimes difficult to deal with, they left me feeling very lethargic with no energy to do thing. I felt that taking the drugswould make me feel better, but they didn't.
205	Mar 29, 2010 4:06 PM	I THINK TABLETS ARE A GOOD IDEA, AS THEY CAN EASILY BE FITTED INTO YOUR DAILY ROUTINE AND YOU PROBABLY WON'T NEED HELP TAKING THEM. THEY ARE ALSO DISCREET. I WAS'NT SQEAMISH ABOUT INJECTING MYSELF AFTER THE FIRST COUPLE OF TIMES, BUT DID NEED HELP WHEN IT CAME TO INJECTING MY BOTTOM. SO SOMEONE ELSE MAY BE SQEAMISH, EVEN WITH AN AUTO-INJECTOR. WHEN YOU GO AWAY IT CAUSES PROBLEMS - DO YOU GO SELF CATERING FOR A FRIDGE OR DO YOU ASK YOUR HOST TO STORE IT FOR YOU? THEY MIGHT NOT LIKE YOU INJECTING YOURSELF? I WOULD NOT WANT TO GO TO HOSPITAL MONTHLY FOR A DRIP - YOU SPEND ENOUGH TIME THERE OR WITH OTHER MEDICAL PROFFESSIONALS. AND IT ISN'T JUST THE TIME IT TAKES FOR THE DRIP, ITS THE RECOVERY TIME TOO. AND HAVING SOMEONE TO GO WITH YOU.
206	Mar 29, 2010 4:34 PM	I have been fortunate enough to have been one of the very first people on the risk-sharing scheme for Copaxone. I have never had a relapse and I believe that is thanks to the medication I take. I would want to be assured that any new drug would be as effective and suitable for me as Copaxone has been.

207	Mar 29, 2010 4:52 PM	The relapses are frightening and I never am quite sure what will happen in the future. Also, I am not sure my medicine is actually going to help me or is helping and I worry about it.
208	Mar 29, 2010 4:57 PM	I havent suffered a relapse for a while I dont think hopefully the drug and lifestyle may be helping. I am taking Avonex again after stopping for a while because of possible misinterpreted side effects. Since restarting the drug and administering by use of an autoinjector in the legs and taking Brufen half an hour before administerinmg the side effects are gone to my knowledge. I have found forgetting Brufen means the side effects return for that injection period (strange but true). I take Avonex because without it there is absolutely no defence against the disease apart from injecting more often!! The new oral therapes would make a magnitude of difference for every reason.
209	Mar 29, 2010 5:22 PM	I developed MS in 2007 and from May to October, both legs were numb from below the knee, it was horrible, like walking on stilts, I could see my toes but was not able to move them. I watched Benny Hinn on the television in October 2007 and he said, "somebody who is watching has been cured of their numbness." A fortnight later, the feeling came back in both my legs so I am convinced he healed me throught the television. I had a stage at Easter 2008 when my fingers became very stiff and it was hard to write so I made myself write e-mails every day and now they are fine. In January the muscles in my back became very stiff but happily I am staying with my family in Dubai till July 6th and with the sun and warmth out here, they are slowly beginning to unstiffen. I was prescribed Gabapentine for burning sensations but after about a week of taking it, I was admitted to Margate hospital as I thought I was having a heart attack as I could not breathe, felt faint and had cold sweats so I am never going to take it again!
210	Mar 29, 2010 5:46 PM	As i said previously i am really scared of needles so would be glad of a pill being available. Also when having a relapse i have to go into hospital to have intrevenous steroids for three days so if there was a pill avalible which would prevent that it would be a good thing,
211	Mar 29, 2010 5:48 PM	I've been injecting for several years now but I was terrified of self-injecting when it was first suggested and am very thankful to my MS nurse for the help and support she gave me
212	Mar 29, 2010 6:15 PM	My MS has improved since I started LDN in Nov.2008.Why don't you do a survey on that?
213	Mar 29, 2010 6:41 PM	is sore and i HATE doing it
214	Mar 29, 2010 6:53 PM	GP's take a reactive rather that proactive line of treatment. Their lack of knowledge of MS symptoms (even if they have the MRI results) does not inspire confidence. If I visit a GP when I have a relapse the first thing they ask is if I would like steroids. More education please.
215	Mar 29, 2010 7:29 PM	I was given Copaxone whilst having Mitoxantrone (which also involved steroids). There was very little information about either of the drugs (I relied on the internet). I had no idea, when I started using Copaxone, how bad the bruises would be up to 12 months after having chemo and would have given the Copaxone up only I thought "persevere, there are people worse off than you". There was nobody to show me how to use the Copaxone as my MS nurse had gone on maternity leave. I had to reply on the DVD in the bag and my own GP nurse (who tried to take the air bubble out). She had never heard of it before. My cognitive problems meant I had to rely heavily on my husband to make sure I was administering it correctly.
216	Mar 29, 2010 7:47 PM	First drug used was Copaxone, which caused "scary" post-injection side effect: shortness of breath, tightness in chest, tightness going rapidly up arms, seemed to lose awareness for short time and was unable to speak (even though I though I was speaking). Also daily injecting was annoying as it seemed to take over my life.

		Now on Rebif. Three times weekly injecting is better and can alter the days if necessary to suit what I'm doing. The downside is I'm still experiencing flu-like side-effects 18 months on - which also takes over my life.
		Difficult to tell if frequency of relapses has changed as I can nearly always detect something going on, but severity is much reduced. Taking Rebif from October 1994 until May 2006 at first was very effective in reducing frequency of relapses.
		From Feb 2004 forward relapses returned with their previous frequency, and when I experienced abcesses that ulcerated on the injection sites, it was agreed that I stop taking the drug.
217	**Mar 29, 2010 8:10 PM**	The act of injecting 3 times per week was never pleasant but it had to be done. An oral version would have been welcomed.
218	**Mar 29, 2010 8:26 PM**	I was diagnosed with rapidly evolving MS in Feb 2009. I started on Tysabri in March 2009 and I have not had a relapse since. I still have problems with my mobility and speech from my previous relapses but after 17 months of sickness absence from work I am finally stable enough to go back to work. That's all thanks to the Tyasbri.
219	**Mar 29, 2010 8:32 PM**	I have had MS 17 years, 12 years Betaferon 1B. Age 38,years old. I absolutely loathe taking injectable DMDs. I fid that If I have had a bad day at work and am feeling stressed and tense then te injection itself is painful -this is followed by approx 48hrs of flu symptoms. Due to these symptoms I have had to go part time at work.
220	**Mar 29, 2010 8:33 PM**	It is hard to explain the impact that having a weekly dose of flu has on your life - suffice to say that it is not a positive one!
221	**Mar 29, 2010 8:40 PM**	The skin reaction at the site of the injection a couple of days after administering Copaxone leads to uncomfortable itching, redness and pain when touched.
222	**Mar 29, 2010 8:49 PM**	Just push for the oral drug to be made available on the nhs.
223	**Mar 29, 2010 9:06 PM**	various problems with my liver enzymes which I understand is due to the drug treatment (rebif) As I never know when the relapses are going to occur, I am afraid to arrange anything in advance - last year I had to cancel 3 summer trips (including a cruise) because of the fear of being unable to cope, which was caused by a relapse just before I was due to go; this resulted in a breakdown. Relapses make sustaining full-time work so much more difficult as they make each day such an effort and I am exhausted, although I still manage to hold down a responsible job. In 10 years of
224	**Mar 29, 2010 9:21 PM**	having RRMS I have not been able to pin down one thing which causes, prolongs or eases my symptoms, which are now starting to include random, sometimes severe, pain.
225	**Mar 29,**	I found that taking paracetamol prior to injecting mitigated the side effects. I took

	2010 9:33 PM	paracetamol during the period of titration and for the first month of taking Rebif at the full strength.
	Mar 29, 2010 10:27 PM	I've been on Rebif for about 7 months. No definite relapse during this time. However I have felt MS symptoms have flared up for a approx 3 week period during this time. Discussed with MS Nurse and we decided not to take any intervention action. Will discuss with Neurologist at next appointment.
226		Its unpleasant having to store my injections (copaxone) in the fridge and having to have a sharps box in my house and to take one on holiday if there could be an effective alternative to injections that would be wonderful !!!
227	Mar 30, 2010 1:45 AM	I have been newly diagnosed with relapsing remitting MS and as yet have not needed medication. But between the last two relapses it has only been 10 months with an increase in symptoms. I am constantly scared about my future as am only 26 and nobdy can give you an answer to how exactly it will progress for me. If there was medication which was available and proved to slow down the occurances of relapses then I feel this should be made available to sufferes.
228	Mar 30, 2010 4:01 AM	Having to deal with the stress of wondering when will the next new symptom appear or reappear one has to deal with the scheduling of medication, pain of the injection and time comsumption of administration once one adds the time to use heat or ice before and after the injection. (40 to 60 mins per day) Then one has to worry about the tissue damage and the ever decreasing number of sites over time. The same would be true of IV administration. Also the rare but nevertheless possibility of infection anytime one breaks the integrity of the skin.
229	Mar 30, 2010 6:47 AM	Only one minor relapse in 9 years - Rebif works for me!
230	Mar 30, 2010 7:52 AM	I have tried hypnotherapy to deal with my phobia of hypodermic needles, but this didn't help. I have seen a therapist/psychiatrist about my phobia, but with limited success. Although my relapses have been less frequent and less severe while taking DMDs, I often wish I could stop taking them, just to get some of my life back. I would much rather take a pill once a day instead of having to remember to do injections.
231	Mar 30, 2010 9:32 AM	Tysabri has stabalised my aggressive MS and for that I am so grateful and now I would like my life to continue without hospital visit after hospital visit if possible
232	Mar 30, 2010 9:33 AM	One of the nasty side effects of tysabri is PML but at least i am surrounded by doctors/nurses when i take drug. I am closely monitored as well - this wont happen taking a pill especially if that pill works in the same way as tysabri.
233	Mar 30, 2010 9:45 AM	My eyesight was very good until I went on Beta Interferon, and then my eyesight deteriorated. After coming off the drug, my eyesight has stabilised, but has not recoved it's previous standard.
234	Mar 30, 2010 9:46 AM	Every relapse I lose a little bit of 'me'.
235	Mar 30, 2010 9:52 AM	In 2007/early 2008 one relapse seem to merge into another and I must have had at least six of varying intensities. Since beginning Copaxone in March 2008 I have had one relapse in July that year but took steroids and carried on working (I had only just returned to work after a break of 18 months). As far as I am concerned, Copaxone has given me back my life although, in some ways it has backfired! While I was poorly in 2007, plans were set in motion to return to my native Yorkshire where I have family to support me and, frankly, I was not expecting to be able to

		return to work let alone maintain it if I did manage to go back. However, problems with the property market delayed my move for many months and I did not move until March last year (2009). At this point I felt disinclined to quit my job and put myself at the total mercy of the benefits' system so I opted to continue in the "short-term" doing a weekly round trip 500 mile commute from my home in Selby (near York) to Canterbury in Kent. Being an English teacher in Further Education and living a short (mobility) scooter ride from my local FE College I expected the arrangement to be short-lived but I find myself still doing this weekly journey (and staying 2 or 3 nights in a B&B) with no sign of an end. (This is both very tiring and expensive!) The problem is that my teaching job in Canterbury has been so diluted - under "reasonable adjustments" - that all chances of career progression have been halted along with slight possibility of new employment. Frankly, it's all rather a mess and, whilst I would not choose to give up the Copaxone, and remain extremely grateful for it, my regret is that I was not prescribed it sooner, opposed to waiting - under NICE Guidelines - for the disabling attacks (which have left me struggling to walk[I use a powered office chair at work and a mobility scooter outside]). With earlier prescribing I would have stood a better chance of maintaining my former teaching role and increasing my hours within one institution (I was previously doing a number of fractional contracts with separate employers over different locations) and following "Plan A". This plan was to increase my mortgage and purchase a flat close to Canterbury College (at the time new appartment blocks were being built opposite).
		So, to sum up, my main concern is for earlier prescribing!
236	**Mar 30, 2010 10:20 AM**	My specialist has not explained or offered them to me.
237	**Mar 30, 2010 10:36 AM**	I take Copaxone. I felt it started to partially work within a few weeks making the relapses less continuous and with breaks in between in which I felt totally normal and not tired, previously I had felt as if something was happening all the time and was continually tired. The relapses gradually reduced to 5-6 week intervals then after 8 months stopped altogether. After a year on the drugs I began to develop serious hives which only stopped when the dose was reduced to 6 times a week, missing 1 day. A daily pill would be great but it would have to have for me at least as good an effect as copaxone but without the hives. Traveling is sometimes a problem as the injections have to be refrigerated when away.
238	**Mar 30, 2010 10:44 AM**	As previosuly stated, injecting daily is both painful and inconvenient. It is somthing that daily I dread, It has howver, seemed to reduce my relapses but it is only an average of 30 per cent The new drugs offer a lot of hope to RRMS sufferers and should be made available to anyone who is eligible for them
239	**Mar 30, 2010 10:56 AM**	It is getting more uncomfortable to inject as the original sites around my body are now dented inwards and are now unsuitable for injection. I have contacted my MS nurse who has given me ideas on suitable places to inject. Unfortunately they are sites I have avoided previously - the sore injection site rubs on my clothes during the day. I injected Beta Interferon (Avonex) for 2 or 3 years as a weekly injection and I was suffering from flu like symtoms and relapsed on a regular basis. Have been on Copaxone for last six years and rarely relapsed, but injections is now uncomfortable on a regular basis. I put Anthisan on the injection site after injectioning which releaves some of the soreness and again the next day.
240	**Mar 30, 2010 11:33 AM**	When i first started REBIF i was happy that i had started some kind of treatment that would reduce my relapses. After a few months my wife repeatedly commented on my low mood including severe mood swings. After reading and speaking to other MS sufferers i came to the conclusion that it was the REBIF that was making me feel this way, so after 3 years of taking the medication i decided to stop injecting my DMD's (without telling anyone). After 2 months has elapsed my wife commented that i seemed happier and easier to live with in general. I then told my wife and MS Nurse

		of my decision to stop taking REBIF. My MS Nurse was fully supportive of my personal decision and so was my wife. I feel that if i had not stopped taking the REBIF then my marriage would have desolved. I now only take PROVOGIL for my fatigue and have not had a major relapse now since i stopped my REBIF in 2007.
241	Mar 30, 2010 12:39 PM	I have noyt had a relapse for many years. Now I worry about my future and the fact that at 68 years old, I am probably too old for treatment.
242	Mar 30, 2010 2:02 PM	the benefits of taking the drug has to outway the side effects
243	Mar 30, 2010 2:20 PM	The worst relapse i had was when i was taken off the drugs after the trial I felt that more damage was caused following relapses during this time
244	Mar 30, 2010 2:41 PM	Avonex was horrendous - it made me ill for two days every week, I was so ill I would have to pay someone to sleep over with me. Side effects would mean my legs would collapse so I would be unable to get to the toilet in the night, I would sweat, shake, my teeth would chatter, every muscle would hurt - awful. Copaxone doesn't give me any side effects, but it's a daily intrusion into my life and makes going away difficult.
245	Mar 30, 2010 4:04 PM	I have had awful relapses, where I have been unable to do anything for myself for months, until relapse passes, leaving you weak, feeling dreadful and depressed. Taking steriods makes you bloated and fat,
246	Mar 30, 2010 4:07 PM	spoke about when was on rebif
247	Mar 30, 2010 4:47 PM	The injections have definitely worked for me as i havent had a major relapse for 2 years but i still get caught out with fatique which is hugely frustrating and limiting my activities with the children the fatique just comes on whether i do to much or not. i still have sensations in face legs and feet and legs play up drag or limp or give way but if rest it subsides. i shouldnt complain as there are friends who have very bad mobility probs. fatique is the main prob for me i am overall pleased with treatment but would love a tab instead of inj. I was going to do a trial at walton for one of the tabs but my blood pressure was too low so couldnt do it.
248	Mar 30, 2010 8:34 PM	As understand my illness will worsen the more relapses I experience. Currenly Avonex reduces my relapse rate by @30 per cent and so any drug that could reduce my relapse rate even further will improve the quality of my future life.
249	Mar 31, 2010 7:55 AM	My relapses are fairly infrequent and I am sometimes given steriods for bad ones.
250	Mar 31, 2010 8:23 AM	The relapses I get with my Progressive Relapsing MS are cognitive and the one I am still experiencing was brought on by stress and lack of sleep.
251	Mar 31, 2010 9:08 AM	I have injectewd betaferon for 10 years now and I regard it as 'my friend'. It certainly appeared to reduce my relapse rat and together with intravenous steroids most of the relapse I experienced were short lived and even though a few symproms remain after a relapse I honestly believe things would be much worse had the relapses been more frequent and allowed to run their course.
252	Mar 31, 2010 2:35 PM	I undertstand these oral therapies are more effective than the existing DMDs. This is why I want access to these drugs. Also I recognise that as the years go on my abilty to inject may reduce.
253	Mar 31, 2010 2:45 PM	I have never been given any medication by my Hospital nureologist and only receive stemetil from my Dr during a relapse.
254	Mar 31, 2010 2:49 PM	I do find that relapses are only a couple of times a year, while administering rebif. I am sure this has helped me to lead a near " normal" life. I do still suffer with flu like symptoms, which i take ibroprofen for.

255	Mar 31, 2010 3:37 PM	I recently had a very bad relapse after a bout of the seasonal Flu. Administering Rebif was difficult as I had little strength to load my medication into the rebiject. A pill would have been so much better. You do not appear to differentiate between an attack and a relapse. They are quite different. A relapse can occur literally from sitting on a hard chair which upsets my system and I then find walking difficult. This tends to ameliorate fairly quickly. An attack (T cells?) is scary. I have in the past lost the use of my legs, my arm, my sight and the ability to go to the toilet. Most of these functions have returned, but not all. Minor disabilities and tiredness are constant. Any tablet which has no, or very limited side effects and stops residual damage is good by me. I have, as yet, never taken desease modifying drugs for MS. My relapses have become shorter and less severe since taking copaxone-from 7-8 wks to 2 wks.
256	Mar 31, 2010 3:39 PM	I still put off doing my injection because inserting the needle hurts and the copaxone stings after I have done it. It is unpleasant and sometimes I just don't want to do it.
257	Mar 31, 2010 3:40 PM	Relapses have become more sevre over time, although taking Rebif has minamised these to nil within the last 14 months. Commencing rebif I suffered flu like symptoms after each injection for a period of 2-3 months, that was 3 times per week. These decreased after I began to take paracetamol 4 hours prior to, and at the same time as injection administration. Now I have no side effects at all. This does noy stop me occassionaly worrying about possible future long term effects.
258	Mar 31, 2010 5:16 PM	I hate having MS I feel frustrated as I am very independent and I am very scared losing functionality. If the risks are proportionate then I am very willing to try new treatments if it means I am able to maintain a more normal life. If there was a high risk treatment which could potentially cure my MS I would seize the opportunity with both hands as I want to be normal again and not have to endure debilitating relapses several times a year, which set me back so far and mean I have rely on others to help me, when I just want to be able to do the things that everyone else takes for granted. More than anything else I WANT MY PRE-MS LIFE BACK, I want my energy, stamina, ability to travel at the drop of a hat, to no longer suffer chronic unending pain, which medication only dulls rather than relieves. I want to live my life without worrying about waking up unable to move, or to be unable visit certain places due to heat or humidity for fear I will be unable to move or suffer more severe symptoms or suffer a relapse.
259	Mar 31, 2010 5:42 PM	I am a young woman and I feel this disease limits my life in ways it should not, I want to take my medication to stay well but I hate having to take injections, they hurt and make a mess of my skin, which me unhappy with my medication.
260	Mar 31, 2010 6:19 PM	Have had MS for 12 yrs, diagnosed at 16. I have never been offered any of the treatments?
261	Mar 31, 2010 6:23 PM	The first two weeks of starting avonex I had the flu like symptoms. Since then my symptoms have been more like a period that is due. Since taking the Avonex I haven't had any relapses
262	Mar 31, 2010	It can be difficult to recognise a relapse and when taking DMT it is disappointing if you do have one. Feel physio support would be beneficial at point of relapse to try to

	6:45 PM Mar 31, 2010	minimise progress of disability.
263	7:07 PM Mar 31, 2010	4-6 week intervals is fine Often my relapses came at night and would be like fireworks going off in my head. I had to walk up and down with the TV on until they went away. Afterwards I felts like I could sleep for a month.
264	7:32 PM Mar 31, 2010	At the time my doctoe prescribed Carbamazepine to control the "explosions" and later Amitriptyline to help me sleep. I was diagnosed in 2007 & have had 3 relapses since. I am a clerical assistant & when I have relapse I lose vision in my left eye - Optic Neuritis, I have pain in my arm, leg & back & chest. The first relapse caused me to be off work for 8 months. The second relapse caused me to be away from work for 4 months. The most recent relapse was - in the words of my Doctor "nipped in the bud". The 5 day treatment of steroid infusion was a great benefit to me & I was only away from work for 1 week. I only work part-time now as the fatigue forces this. When I am tired I have more apparent congitive issues at home & work. I also stumble on a daily basis as my balance is very poor. My next appointment is with my consultant on 19th April & I am hoping he will change the current medications to prolong remissions between relapses. I take 225mg Pregabilin twice daily. Also 1 Modafinil tablet daily & 25mg Amytryptaline & .2micrograms of Desmopressin at night. I hope this will help with your study.
265	8:24 PM Mar 31, 2010	I have only been taking Avonex for six months and, so far, it has been effective. Being told I would have to inject was probably harder for me than being told I had MS. Even though you have to get used to it and appreciate being offered the drug, it doesn't make it a pleasant treatment experience and the side effects generally mean that one night a week is written off as you feel lousy.
266	8:49 PM Mar 31, 2010	The stress and anxiety caused by injections has almost as much effect on my quality of life as the MS condition itself.
267	9:13 PM Mar 31, 2010	Feel injections may trigger relaspse
268	10:22 PM Apr 1, 2010	What a nice section that you've put here, so I can tell you what I really think. I'm far from being alone, though. The MS Society can ONLY redeem itself, if they get on-board with the rest of the world in regards to CCSVI and the treatment to fix this VASCULAR CONDITION. That way, and ONLY that way, you can really prove yourselves as being there for MS Patients, and really wanting a cure. Come on, folks, get with it. Read Facebook... We're there and we're completely FED UP!! Look at the ms-ccsvi-uk page... you'll learn more than you ever imagined about the people you supposedly are supposed to be looking out for.
269	12:44 AM Apr 1, 2010	I live overseas with no family support around me so simply have to just get on with life and do everything for myself. With a positive frame of mind it's entirely possible. When my legs get so heavy and walking is difficult, I shake it off and force myself to carry on. I feel injecting with Rebif is keeping the MS under control (to a point). I obviously don't know much about the new pills because if the drugs being injected are 'disease modifying', aren't the pills a 'disease modifying' drug as well? For me, it's purely if the pills do the same job then 100 per cent I'm all for it as there are very few parts of my body left to inject without pain.
270	6:59 AM Apr 1, 2010	I would be very resistance to any suggestion to move from Rebiff to one of the oral compounds as I have not had a relapse for over three and a half years and whilst I still suffer from side effects, flu like symptoms and injection site reactions these are easily managed. I have great concerns tha the oral drugs are going to be pushed as the best treatment available but am concerned about there safety.
271	10:10 AM Apr 1, 2010	I hate the pain of the injection, then the side effects, it is an awful experience and so disruptive.
272		

	10:33 AM	I found the flu-like side effects a major issue, all the other inconveniences and side effects were bearable. So for me, administering the injection, was NOT my biggest concern. If the drugs worked and didn't have such awful side effects (for me) then I would happily inject on a dialy basis.
		In the 2 1/2 years I took interferons I had no relapses - since stopping I have had many - I now take LDN which definitely helps and has no side effects.
273	Apr 1, 2010 11:17 AM	If the new tablet has the same side effects, the fact that it was a tablet not an injection would not encourage me to take it again.
274	Apr 1, 2010 12:29 PM	It was very frustrating when I had to wait the six weeks coming off Avonex (by the time I started on Tysabri I was in the middle of another relapse). That was the last relapse I had a year ago (fingers crossed it continues for a long time like this).
275	Apr 1, 2010 12:38 PM	I take a weekly injection. I dont suffer strong side effects but the following day is a bit of a write off - like a minor flu, tiredness and headaches etc and difficulties in concentrating. I can do very little on that day. To help ensure I can contnue with work I inject on Friday evenings which means that I get a 1 day weekend (the Saturday being a write off). I live with this but it can be very tiring and draining - physicaly, mentally and emotionaly.
276	Apr 1, 2010 12:56 PM	I was taking Avonex briefly but found the weekly stress of worrying about doing my injections was too much. I know can't even let anyone else inject me. I could cope with the side effects of taking the DMDs but just not the physical act of injecting. It now worries me that I am not on any medication at all.
277	Apr 1, 2010 1:46 PM	I've often been prescribed steroids for relapses, and even with the extra side effects that come with taking this orally I am very please that I haven't had to go to hospital influsions that I so often see people taking
278	Apr 1, 2010 2:03 PM	too scared for the injections !
279	Apr 1, 2010 3:02 PM	Am awaiting to see about drug therapy after my diagnosis in December last year.
280	Apr 1, 2010 3:51 PM	I cannot stress enough the problems that revolve around holding down a busy and stressful job and the effect that medication has on this. The injections never improved for me and I took time off due to the flu reactions, as the benefits never outweighed the bad reactions. A pill would allow people to manage to retain their jobs for longer - I am currently struggling to hold manage my job and would not be covered for a hospital appointment every month - I would have to take 12 days out of my holiday to cover this (or a minimum of 6 days - 12 half days). With my relapses increasing and the fatigue symptoms ever growing, help managing MS is vitally important.
281	Apr 1, 2010 4:12 PM	I have only recently been diagnosed with MS (4 months), however have retrospectively been diagnosed as having it for 5 years. The fact that there is disease modifiying drugs out there is wonderful. The fact that most are injections is less so. I have had varying side effects with my avonex, but realise its worth the perseverance in order to sustain my current level of health for as long as possible. I have been told by several medical proffesionals that I should be able to lead a 'normal' life, while this isnt strictly true as I have to loose part of my weekend to avonex side effects, a pill based drug would potentially re address this.

		Its clear even to me that a pill would be 'cheaper' to distribute, administer and ingest/recieve.
282	Apr 1, 2010 4:22 PM	It seems to me like a win win situation for everyone involved. I did take a break for a year from injecting Copaxone but was persuaded by my family to start back on it due to a relapse at the end of last year. I had forgotten how difficult it is to inject and now realised that my reasons for coming off it have not changed but I will continue for the sake of my family and the hope it is doing me some good in reducing relapse rates. I do not like the sore lumps and stinging from each injection and have been told they will reduce over time which I seem to remember I was told last time.
283	Apr 1, 2010 5:23 PM	One experience I had about 2 years ago involved and injection site becoming infected causing a cyst on my stomach. When the pain became excruciating I ended up in A&E at 2am having it lanced under local anaesthetic. This resulted in me having weeks off work (unpaid), a district nurse having to visit every day to dress the wound and I believe the incident triggered a relapse which has left me unable to use my right hand to write with ever since. So all in all, I can't imagine taking a pill would cause such disruption (and pain!)
284	Apr 1, 2010 5:56 PM	I have always gone 'in denial'. If I would realise what was happening maybe I could alleviate some of the effects and pain.
285	Apr 1, 2010 6:58 PM	I have never taken drugs but Anandin extra does not get at the pain. When using avonex I became very anxious about the jag and how I would feel the next day after using it. I recently changed to rebif, but don't know if the muscle pain in my legs is a relapse or caused by the drug.
286	Apr 1, 2010 6:58 PM	Injections can be very painful at times, they have caused unsightly lipoatrophy - they have been difficult to transport when on holiday, as we spend our holidays camping We have had to limit where we went camping in Europe to camping sites where we could have electricity to connect to a reliable fridge which we needed to buy transport the drug. We had a fridge failure in a heatwave year (that is the only couple of weeks I have missed taking the drug) and upgrading the fridge and electrical connections was expensive and takes up a lot of space to transport it all. Not at all convenient.
287	Apr 1, 2010 7:25 PM	I take Rebif and have had 2 relapses in the last year.
288	Apr 1, 2010 8:32 PM	I have been taking Avonex for six years but I still get flu like symptoms after injecting and also a red skin reaction at the injection site. My Neurologist says that this proves that I have not developed neutralising antibodies. This does not make me feel better about it! I dislike injecting because no-one else I know has to take medication in this way, it can also be quite painful. It makes me feel different from everyone else and there is no sign that it works. Occasionally I forget to inject before I go to bed by which time it is too late to do it that day. A pill would be so much more convenient as it would not need 30 minutes to come to room temperature.
289	Apr 1, 2010 9:40 PM	I like taking my disease modifying drugs . I feel at least I am doing something to fight this horrible disease.
290	Apr 2,	Th intervals of my relapses has been so close lately having been confined for almost

	2010 2:50 AM	twice a month.My Neurologist can't easily bring me back to Betaferon or Interferon or any MS disease modifying drug available in either Europe, U.S. or Canada because aside from we still have to order the med abroad, the cost of the med when it arrives here in the Philippines becomes skyrise. The irony of it all, Philippine government doesn't support patients of unknown specialty disease like MS. I had two relapses last year one straight after the other. These relapses can be very debilitating and take away your independence. I work part-time and when I have to have time off sick I feel I am letting people down. I am a Staff Nurse and am currently undertaking light duties as my mobility is not what it was. This upsets me greatly as I feel that due to MS I am unable to do the job I have so enjoyed for the last 8 years. I feel at the moment I will not be going back to my role as a 'Nurse' but taking on other tasks within the nursing team, I know this will be better for my health at this time.
291	Apr 2, 2010 10:51 AM	I am currently taking Avonex and have been on this for the past 3 years. I do these injections myself as I prefer it that way. It is not a pleasant experience and when I do have relapses I sometimes wonder whether this medication is working for me and is it worth the pain!!!! I am really hoping that oral medication would be available for me in the future.
292	Apr 2, 2010 11:51 AM	A reaction to Copaxone I have had three times in a year and is the scariest thing I have ever experienced. Afterwards it does make you feel wary when the next injection is due.
293	Apr 2, 2010 3:10 PM	each week on injection day i am allways reminded of my ms and the anxicety returns. it would be so easy to pop a pill.as im sure it would for anyone who has tio inject. Since starting daily injections of Copaxone I have had no relapses at all, whereas prior to this I had many relapses in close succession.
294	Apr 2, 2010 5:19 PM	Needing to give myself an injection after a long day (e.g. after a party, night out, long journey) can be difficult. Carrying all the paraphernalia - cool box, injector, sharps box, et al - when going away can be a nuisance, frankly. Finding somewhere private to inject isn't always easy. I can't Inject in some parts of my body myself, so need to rely on someone else (who isn't always around). Although I have had few relapses, I feel that the treatment with steroids which I received caused permnent damage - i.e. digestive problems, thinning of the skin and of the veins.
295	Apr 2, 2010 7:55 PM	I feel that the medical profession is often reluctant to explain the problems which can be experienced with treatments. The more clear the explanations the better.
296	Apr 2, 2010 8:35 PM	I have only recently been diagnosed and as of yet I don't know what type I have. At the moment I am very worried about my future and that of my family. I have recently moved a hundred miles away from my family and friends to start a new job and a new life. I had symptoms of Optic Neuritis on 20 Nov 2009 with white lesions shown up on my MRI. I was told that I could be given Cladribine but only within a 90 day period. I was also told that I might not even have MS and might not have any further symptoms. When I asked the question - when I have my second MRI in 90 days and if there is further white lesions could I start Cladribine I was told that this was not possible. I have now had my second MRI and it shows new lesions, I now cannot have the treatment that I want (Cladribine) so have to wait up until maybe a year when it might be legal to prescribe in this country - in the mean time my disease is as my neurologist puts it "slowly bubbling away"
297	Apr 3, 2010 10:16 AM	Please make this drug available so people like me can continue to get on with our lives with the reassurance that we are taking the best drug available in slowing down

		the progression of this disease. Thankyou.
	Apr 3, 2010	The DMD I am on has not worked and I cant take the others due to the side effects that I worry about. My recent relapse has meant I now cant walk, but maybe i would be walking if these better new drugs were available faster.
298	10:30 AM	I don't believe any of the DMD are good enough to help with my MS
299	Apr 3, 2010 12:06 PM	I find it very hard to deal with self injection and would be extremely happy if I could take a dmd orally.
300	Apr 3, 2010 2:21 PM	I had my second attack last year in october, i was given steriods which helped greatly reduce my symptoms and stabilize me, i however still feel fatigue and run down a lot but wont go to the doctor unless i get severe pain and numbness because i have a far of facing the injections frequently and the thought of the lack of options available makes me not want to discuss my problems with joint pains, sometimes numbness etc.
301	Apr 3, 2010 2:56 PM	I am a resident in Scotland. The treatment I have recieved has been excellent. The service from Clinovia and BUPA over delivery of the drug has also been first class. There is regular dialogue between the drug company and the specialist MS nurses. m Further i have moved inScotland from one health board to another area and the MS specialist NHS treatment was absolutely seamless and straightforward.
302	Apr 3, 2010 3:01 PM	Injections are painful I have ended up with bruises, red marks and blotchey skin. I also got asked if I was a drug addict by one lady.its inconvenient and it constantly reminds you about your illness.during a holiday I had to go back to the hotel to adminster my injection, then there's having to get a letter and getting taken aside at the airport like a criminal.
303	Apr 3, 2010 3:21 PM	Must admit I am happy to use Copaxone as prviously I was experiencing a lot of relapses ant these have lessened a great deal since I started on Copaxone. It is a great drug for me. I would love use a a pill as giving myself injections is so unpleasant---- and leaves me with sore patches
304	Apr 3, 2010 3:38 PM	I have had bad ractions from taking my rebif in injection form and on the evenning of taking it,my body wants to shut down and not let me do alot,so it becomes very frustrating and i am becoming resentful of it,as i would like to be able to go out in the same evenng...
305	Apr 3, 2010 4:00 PM	I am very pleased I am using Tysbri as it was my only option when my MS started to get Progessive Remitting Relapes. But I have to take a day off work every 4 weeks and travel to London which is expensive. I also worry about the risks and what it is doing. We need these drugs to be cleared by NICE to get my life back.
306	Apr 3, 2010 8:00 PM	I had a very good relationship with copaxone and suffered very few and only mild relapses whilst I was on it. I felt I was almost cured. But I had sudden occasional attacks of chest tightness palpitations flushing and finally severe muscle spasms and pain in the muscles of my back and base of back causing me to worry about my safety if I continued to take the drug
307	Apr 4, 2010 7:23 AM	I'm not currently on any disease modifying drugs becasue I haven't been diagnosed very long and we are waiting to see how frequently I have relapses. I currently take medication to help treat some of the symptoms I am left with permanently, but they don't help at all when I have a relapse. My specialist is hopeful that the tablet version of the medication will be available once we are in a position to make a decision about diease modifiers. I want MS to have as little impact on my life as possible - but that's proving to be a real challenge. Trying to hold down a job with MS (and employer's and colleagues' attitudes towards it) the debilitating effects of relapses and trying to live a normal life is very difficult. I'd welcome anything that would make it easier and 'normalise' it.
308	Apr 5, 2010 8:29 AM	die genannten medikamente sind eher schädlich,da ms keine autoimmunerkrankung ist sonder venösen ursprung ist

309	Apr 5, 2010 10:28 AM	i take ldn but not being well off i strugle paying for script and ldn could do with help thanks mjherbert
310	Apr 5, 2010 11:33 AM	I have no side effects using Copaxone - however I do not feel any effects at all, and has not stpped my condition worsening slighty
311	Apr 5, 2010 7:11 PM	The relapses are very distressing and completely disrupt my life. I find it difficult to plan anything such as a holiday due to the uncertain nature of MS. Taking syringes abroad is a nightmare, an oral drug would be much better. The injections are difficult with the numbness in my fingers and hands.
312	Apr 5, 2010 7:47 PM	Copaxone bruises me and gives me very hard itchy skin.
313	Apr 5, 2010 8:53 PM	I had taken Avonex for 19mths and then experienced tripping up and leg stiffness and loss of balance came off the drug for 10months and started Rebif and took it for 13months still have leg stiffness. Stopped Rebif 3 months ago and my walking is much the same but my balance has improved, but I am experiencing more numbness in my fingers hands and feet. I may have to start back on Rebif, but I would prefer if it was in tablet form for the long term medication.
314	Apr 5, 2010 9:27 PM	Avonex was so wrong for me ,I became scared of the deep injection & my husband often had to do it for me.The side effects were awful & I was so miserable in the end I had a break of around 4 months then went on to copaxone. I now feel ruled by injections in a way that I do not feel by various oral tablets I take for ms symptoms.I have often felt like giving up on injecting but continue as there is no alternative & I want to lessen my chance of relapse,but I would benefit so much from an oral drug.My quality of life & body would be greatly improved. Surely an oral drug will be cheaper too in the long run.
315	Apr 6, 2010 4:09 AM	I was on beta seron, never fellt any benefit from the drug, but experienced many side effects
316	Apr 6, 2010 9:45 AM	I do think the medication works as I haven't been hospitalised for s few years.
317	Apr 6, 2010 12:29 PM	just been diagnosed
318	Apr 6, 2010 2:31 PM	I
319	Apr 6, 2010 4:18 PM	only had about 2 relapses but have had cancer twice over last 9 years slowed me down a bit more.
320	Apr 6, 2010 6:41 PM	when i have relapses the dmd makes the relapse worse after administration.
321	Apr 6, 2010 7:09 PM	Since using these drugs my MS has improved and I have spent more time in remission than previously this was also shown when I stopped taking the medication for 3 months and then experienced my first relapse in 18 months
322	Apr 6, 2010 7:40 PM	Copaxone has left 'dipping' all over my body, (legs on both sides, buttocks on both sides) and although Tysabri seems to be working, it doe take two days out of my month, so a tablet would be so much easier to manage. It would also allow me to manager my life a little further. However.....Tysabri works for me and does seem to be preventing this from getting un-manageable, so unless the tablets does

		the same would stick with Tyasbri. I am also aware, this does not work for all, but it does for me!! I have tried rebif and liver function was out to often then tried copaxonne but had to stop due to injection site reations.Later found out i have diabetes which may have contributed to skin taking longer to heal. I now take no diesese mod drug and am having a relapse for the first time in a few years.
323	Apr 6, 2010 8:46 PM	A pill would be a wonder. The effect of the unpredictability of relapses is at times challenging and distressing. The impact is not only on myself but on family and friends. I find the treatment of steroids for relapses extremely unpleasant. I often have a low lymphocyte count (which brings different side effects) as a result of the Avonex and have occasionally had to have a break from treatment. The decision to continue with Avonex is 'on balance' with the hope that it reduces frequency and severity of relapses, as the side effects of the Avonex also impact on daily living. Any opportunity to reduce these negative results would enhance my life. I remain very active and have a positive approach to life but believe if there are alternative treatments that reduce the negative aspects of both relapses and current treatment this has to result in a reduction of costs to the NHS and Social Care system as a whole.
324	Apr 6, 2010 8:55 PM	
325	Apr 6, 2010 10:23 PM	I would like my life and my future back. The relapses have not ceased. I was free for a while when having treatment with Mitoxantrone and just after. It is milder but there's a gradual downturn again.
326	Apr 6, 2010 11:29 PM	There MUST be something better. What is the comparative cost? I wonder...
327	Apr 7, 2010 8:20 AM	Really bad side effects, bruising horrific that leave lasting bruises and soreness - looks wierd and makes people look at you funny. I never really experienced major relapses per se, even before the drugs. Have been dxed 20 years. I used to get flare ups for the first 5 years or so whilst taking meds I would get the standard symptoms but nothing major. Have been without meds for 2 years and not had any major incidents. Very scared about where this is going.....
328	Apr 7, 2010 8:46 AM	
329	Apr 7, 2010 10:39 AM	My drugs work at slowing the eventual, and guaranteed, development of my MS. In this situation I'm VERY prepared to feel crap for 3 days rather than 7 per week
330	Apr 7, 2010 11:12 AM	I have questions about whether the drug is working versus the relapse is not as bad / not as frequent as it could be if I weren't on the drugs.
331	Apr 7, 2010 11:27 AM	needles also scare/worry others
332	Apr 7, 2010 11:56 AM	Still having side effects even though i have now been using avonex for six years. I administer Rebif manually on a Monday, Wednesday and Friday, and always feel more poorly on these days, i.e. more headahes and even Migraines which I never suffered from before. I am currently relapsing and feel very poorly. I am currently taking Pregabalin to ease the pain, but I feel I'm getting worse, not better. I see my MS nurse on Friday, and will raise these issues with him. I am going to enquire about LDN, as this seems to be the only drug which is having any positive effect on MS symptoms.
333	Apr 7, 2010 11:58 AM	I use hyperbaric oxygen and have only had two or three relapses While using it for the last ten years
334	Apr 7, 2010	

	12:13 PM	
335	Apr 7, 2010 1:21 PM	I have only been taking Copaxone for 6 months, but it has made a significant difference to my overall health, and I have felt much better since taking it. It hasn't solved all my relapses, but it has certainly helped. I don't find the injections arduous, although remembering to take it out of the fridge in time to come to room temperature can be a challenge!
336	Apr 7, 2010 1:46 PM	from being on these ijections for 5 years I have lumps, bumps & redish/purplish marks over my buttocks and abdomin, they are quite sore and very unsightly. It is very often painful on injecting. I am not 100 per cent sure what course my disease would of taken without these drugs but I, myself do feel they have helped immensley.
337	Apr 7, 2010 3:14 PM	I have been taking Copaxone for 7 months and am just experiencing my first relapse since commencing the treatment. Previously, relapse 1- May 2004, relapse 2- Dec 2008, relapse 3 -April 2009, relapse 4- March 2010. There has been a wider gap between relapses since Copaxone than immediately prior to starting injections. I make an assumption that I may have relapsed before now and/or that relapse could have been more severe than without Copaxone. This currnet relapse has been described by a neurologist as a bad brain-stem relapse and has therefore affected several aspects of my daily life including marked speech slurring, pain, mobilty and severe fatigue. Aside from itchy, raised lumps on injection site that are just beginning to be less pronounced, I feel that I have not experienced any side effects.
338	Apr 7, 2010 3:43 PM	I have been on Copaxone for nearly a year now and during that time I have suffered a few relapases, which have required IV steriods. I think Copaxone has probably helped reduce the severity of the relapses but I need to self inject every day and use different sites each day which takes some planning and organisation.
339	Apr 7, 2010 4:26 PM	Relapse are horrible. They scare me and my husband. We are never sure how much more disability I will gain or whether I will improve at all. They take months and months ut of my life and often a year or more to get better.
340	Apr 7, 2010 4:47 PM	I had a total of 13 relapses over the first 2 years of being dx I was on Avonex for 1 of those years but I was still having relapses I started Tysabri on August 08 and haven't had a relapses since the Tysabri has giving me my life back
341	Apr 7, 2010 5:17 PM	injections frighten a lot of people even my children know I do it but will not see me do it so taking a pill would be great. Plus, you can take the pills out with you.
342	Apr 7, 2010 6:40 PM	i started taking avones combined with metylperdeniloson in high dosag from 2001 as i get diognised as the same year in 2005 i lost my eyesight which again having streoid injection for 5 days in hospital 2 times a day i got back to normal.in 2007 i stopped taking the treatment comletlyin 2010 i started having trigiminal neuroligia which lookes like another relaps because i became paralise in my left side of my body
343	Apr 7, 2010 7:28 PM	I have been told by my consultant that I have to come off tysabri by the end of this year, so getting fingolimod licensed as soon as possible is important because tysabri has changed my life for the better and to lose that is going to be very hard. The only thing is that I have been told that I have to be off tysabri for a minimum of six months so not looking forward to that period with no meds.
344	Apr 7, 2010 8:53 PM	I would like to be able to try LDN as it seems to have worked for so many MS sufferers, so far no drug treatment I have expreienced has had any positive effect on my MS symptoms
345	Apr 7, 2010 10:04 PM	I feel very lucky to have the ease of use with the Rebismart and not having to be the 'patient', I can do all of my injections myself. However, my arms and legs are dotted with skin reactions, when I wear a swimming costume on holiday, I feel I need to

		cover up all the time. I would welcome an oral drug, so long as the side effects were similar, so that I could lead a more normal life.
346	Apr 8, 2010 9:39 AM	Lack of support from GP (pleads ignorance), instead referred to specialist (a long journey away) for answers - cannot get appointment with specialist just have to wait my turn months ahead. Regular contact from somebody/anybody would be good - just a phone call. Support is needed generally for people with MS - it can be very lonely.
347	Apr 8, 2010 10:09 AM	I AM NOW 53 HAD MS SINCE i WAS 16
348	Apr 8, 2010 2:57 PM	To date and extremely fortunately, I only have monthly B12 injections
349	Apr 8, 2010 3:52 PM	Every time I have a relapse I worry that i won't recover from it. Always leaves me physically worse off than I was before, so it's really important to me that I am on the drug that most effectively prevents relapses.
350	Apr 8, 2010 3:59 PM	I was stopped from taking Betaferon due to attempting suicide after 6 months of being on the drug. I was then commenced on Copaxone, but continued to have regular relapses despite being on it. It was then decided that commencing Tysabri would be the best option. I now have very few new symptoms and have only had 2 relapses whilst taking this drug - although I do worry about PML.
351	Apr 8, 2010 4:29 PM	As I expected, none of the drugs have improved my disability, but I feel at last that I have plateaued.
352	Apr 8, 2010 5:00 PM	I can be kept awake at night unable to sleep, due to the side affects of my Rebif. Therefore making me much more tired the following day.
353	Apr 8, 2010 6:18 PM	i always tolerated the drugs pretty well
354	Apr 8, 2010 9:55 PM	Mot convinced these drugs actually work
355	Apr 8, 2010 11:53 PM	One of my relapses that i had a few years ago was in my eyes. Everything was out of focus and i couldn't see anything past a certain point at the corners of my eyes. I felt very frustrated and depressed as i had only just gotten over a previous relapse in my leg and couldn't feel or use it properly for a few weeks. Having to try to inject myself only made me feel worse.
356	Apr 9, 2010 6:05 AM	Capoxone has had such a positive impact on my illness in terms of fatigue and my general well being. I'd love to take a drug that improved my health to this extent, with minimal side effects in oral form.
357	Apr 9, 2010 10:53 AM	In all examples a MS sufferer including myself feels isolated - there is no practical support system and very little understanding amongst others about this disease.
358	Apr 9, 2010 11:26 AM	Please live our lives for a day.
359	Apr 9, 2010 12:10 PM	i worry about drug dependency for this illness and especially if efficacy has yet to be proven.
360	Apr 9, 2010	Each injection site becomes sore and swollen. I have had horrific skin reactions with my skin coming apart, being infected and now scarred. I do believe in the medication which is the only reason that I can continue with the injections because it is keeping me well but it does takes its toll on all aspects of my life. Im am truely hoping that it will become available to me in tablet form. I have never had any side effects with taking this drug. I just cannot bare injecting my self and a pil would be so simpler.

	12:36 PM	
361	Apr 9, 2010 1:02 PM	when I first started to inject with avonex I had mild side effects but after injecting for 18 months the side effects returned with a vengance I was completely unable to function for 3 to four days after injecting. I was then put on copaxone but I had severe injection site reactions which resulted in having to take steriods to clear up the injection sites. As a result of this I haven't been taking any modifying drugs for approximately 2 years and boy do i know about it because the relapses are coming thick and fast. Re relapses - unpredictability of them - dont know whats round the corner.
362	Apr 9, 2010 1:45 PM	Re Avonex - often experience mega 'hangover' feelings morning after, but not moaning as know Im one of the luck ones who've been given chance to take it. in my case , eventually my blood readings became abnormal. I am actually quite gratefull that there is a treatment that has worked for me (15 months no relapses) , on betaferon. Although you wonder , in this day and age a pill cannot be made more available. Betaferon is a delicate substance. My job and lifestyle require(d) extensive travelling and this is curtailed by MS and carrying betaferon. If there could be a "normal" stable version i.e. a pill , i could potentially go back to having a normal lifestyle and contribute again.
363	Apr 9, 2010 1:52 PM	I am saddened that i inject every day knowing that the drug i am injecting can only reduce relapses by a third....which seems a small return for the pain, trauma and anxiety I put myself and those around me through to get it into my system!
364	Apr 9, 2010 2:51 PM	I expected it to have worked by now but the MS nurse said it may be working where I can't see it
365	Apr 9, 2010 3:26 PM	i dont think we get told enough about why a consultant has chosen the 1 he puts you on , and i dont think you get enough support after a relapse and you can never get a ms nurse at weekend and its not like to plan to have a relapse at weekend I have been very fortunate. During the time I have been taking REBIF I have had no major relapses and this followed a few years of relapses and steroids etc. I am not oblivious to the fact that I may still have relapses in the future and I do have to endure the effects of things that have happened in the past.
366	Apr 9, 2010 3:44 PM	I am also astounded by the industry that is around the medication. Private nurses coming to the house to train you to use it. Refrigerated delivery vans to the house. Dedicated phone lines with the manufacturer and distributer. Monthly sharps boxes and disposals. My GP told me, because it came up on his system, even though he was not paying, it cost nearly a thousand pounds a month. That is a lot of money to pay out on any person in a credit crunch! And that does worry me. This drug has helped change the course of my MS and I have the distant worry that it might be withdrawn.
367	Apr 9, 2010 3:54 PM	disease modifying drugs have been very helpful for me but injecting is uncomfortable and i have had some side effects and skin problems, however i feel it is a small trade-off for the effect of being well.
368	Apr 9, 2010 4:17 PM	i would be very interested in taking a pill instead of injecting but would also be anxious now about changing my treatment in case it affects my health and causes a relapse.
369	Apr 9, 2010 4:29 PM	The Rebif was unsuitable for my body to cope with the awful side effects. I then went on Capaxone which to date I tolerate, but due to injecting I am getting problems. These range from injection site swelling, irritation, redness, and muscle loss. I have found due to taking Capaxone I have suffered far fewer relapses.

370	Apr 9, 2010 4:56 PM	I have been on Betaferon since Sept 1996. I used to have 3-4 relapses a year I have not suffered any since starting the treatment. My walking ability has slowed down over the years and I tire easily when doing housework but this is nothing compared to the way a relapse affected me.
371	Apr 9, 2010 5:59 PM	I am at the moment in a very bad relapse i can hardly walk now and in a lot of pain and bad spasticity
372	Apr 9, 2010 6:07 PM	After experiencing really nasty site reactions, panic attacks, fainting and therapy sessions and seen the stress this has caused to my family (and to myself), the thought of being free of all this fills me with hope. Every time i have to inject I wish there was another way.
373	Apr 9, 2010 6:20 PM	I was very fortunate, in that I was given the opportunity to try Rebif quite soon after diagnosis. It has worked incredibly well for me and has (in my view) reduced my relapses by 80 per cent. I have never had bad side-effects, but just get big red blotchy marks. That's nothing. I used to have to pay for it and it cost a great deal of money. The risk-sharing scheme was a life-saver. I have only 3 more lesions in the last 10 years and 4 significant relapses. t relapse causes permanent damage - so for me, relapses=damage=progression. The damage is slight, compared to so many other more disabled people. I have balance problems, memory loss, neuropathic pain, hemiparesis and some vision problems and fatigue. I can't work as a classical musician any more as I just don't have the inner strength. The invisible symptoms of MS can be awful and as they are invisible, how can you quantify them? I would not like to try to apply for benefits as I can't prove to someone how much MS has changed my life. Without Rebif, I am sure that I would not be able to walk. I also take LDN which has given me back full bladder function, which is an incredibly important factor for people with MS. Removing the risk of having to use catheters may even save me from an early death. At the time of my diagnosis in 2000, the MS Society was not a big part of my life. The perception of the MSS was that it is very medically conservative and only interested in paliative care. Things have improved. Thanks to the message forum, we can swap information and experiences and I have learned a huge amount about MS. Back in 2001, the 'other' MS charity with a magazine (New Pathways) was very anti-DMD and this was a cause of great emotional discomfort. I still haven't forgiven them for their attitude and probably never will. At least the MSS discusses other treatment options and although it can't endorse

		alternative therapies or drugs as nothing works for everyone, at least they have had the open-mindedness to discuss drugs and therapies and for that I thank you. For me, Everyday Living is a lifeline. I would like to say a million thanks for this website.
374	Apr 9, 2010 7:04 PM	waiting for liberation treatment...hoping to forget about the drugs
375	Apr 9, 2010 7:12 PM	I am currently on the Dacluzimab drugs trail.
376	Apr 9, 2010 8:06 PM	Although I was offered disease modifying drugs in 2005, having at that stage had enough relapses to qualify, in consultation with my GP I decided that it was not appropriate for me. I went instead to the Royal London Homeopathic Hospital, who discovered a vitamin deficiency which is now being treated, as well as prescribing homeopathic remedies. I have not had a significant relapse since.
377	Apr 9, 2010 8:20 PM	I have never been offered any DMD's in the 7 years I have been diagnosed. It saddens me that I now find that they arent recomended for people after 6 years DX and feel I have "missed the boat".
378	Apr 9, 2010 8:47 PM	To take a pill would be more comfortable, than having an injection, and dreading the side-affects that you know come next. My children would benefit from this as well i think, as they know what to expect from their mum on my chosen day. This injection always affects me the next day.
379	Apr 9, 2010 10:48 PM	you have nothing to compare it to so difficult to judge what impact it is having you just hope it is having some effect on reducing the number and severity of relapses. A pill would be wonderful.
380	Apr 10, 2010 2:57 AM	our neuro and their nurses should be supportive, I know our NHS is going through rough times but things are changing slowly but surely i hope
381	Apr 10, 2010 8:28 AM	Infections and bruising in the injection sight.
382	Apr 10, 2010 8:45 AM	I have had to seek help for depression and feelings of worthlessness, due to a feeling that there was no way to cope with this debilitating disease. Any treatment that would improve all MS sufferers quality of life must surely be considered as worthwhile. Pain and fatigue can be almost unbearable. I know what it's like to have to stay in hospital for drug treatment (steroids), and to have the option to self medicate, without needles or stayover, would be immensely positive.
383	Apr 10, 2010 10:26 AM	Only as per the last question box.
384	Apr 10, 2010 10:40 AM	A relapse for me is overwhelming, affecting my physical mobility by 75 per cent+ e.g. I can't even crawl very well to get to the toilet
385	Apr 10, 2010 12:10 PM	I'm afraid of needles so self-administering Rebif/Copaxone was a horrible experience for me. I experienced the post-injection reaction associated with Copaxone (feels like a mixture of heart palpitation - asphyxia - anaphylactic shock!) which was pretty terrifying. The tissue on and around injection sites is permanently damaged from sub-cutaneous injections. Switching to weekly intra-muscular injections (Avonex) has been better but I need to go to my GP for the injection as I cannot bring myself to do it. I also suffer muscle spasms and debilitating flu-like symptoms after the treatment, this still occurs regularly despite being led to understand that the side effects would disappear over time (I have been taking Avonex for over 2 years now).

386	Apr 10, 2010 1:46 PM	Can not add anything at the moment as due to embark on a course of disease modifying drugs
387	Apr 10, 2010 2:01 PM	the issue of delivery means you have to plan and arrange, life would be easier if you could pop down the chemist for a few pills. At present I am waiting to see my consultant regarding injection side-effects (Betaferon). After a number of years injecting, I seem to be having side effects (legs seem to be extremely heavy and awkward to move and sometimes I cannot move at all, like I am paralysed. This makes me feel very angry and takes away my independence. I am told that nobody else as reported any similar problems (I am aware however, of other patients coming off the injections due to similar problems). The injections now cause me to have a bad day, every other day, this as a massive impact on my working life and more importantly my home life. I am lucky that I have an understanding employer who has agreed for me to work from home part of the week and when I am having problems (mobility wise). This I have found very useful, helping me from a fatigue point of view as well as allowing me to continue to work. My independence is very important to me, as is my family. I have no problems with needles and although sometimes awkward I am not bothered about injecting myself.
388	Apr 10, 2010 2:12 PM	In saying that not all people are as easy with needles or injecting (as a personal friend of mine, panics every time they have to inject). Therefore, an oral form of medication would seem an easier solution to the current form of injection.
389	Apr 10, 2010 4:41 PM	ms is very life limiting and if you have ms you need all the drugs available to deal with this condition and taking a tablet would be so much better I'm 25, I started on avonex and stayed on it for as long as I could even though I missed two days out of every week because I suffered really bad migraines, felt sick and was really nasty, so I had to stay in bed all because I'm scared of needles and did'nt want to have to inject myself. Then I plucked up the courage and stared copaxone, I kept getting infections, It got to the point it was one every week, then I went on rebif and I got really depressed and when I was'nt depressed I was really nasty so I'm off them now and not doing well at all, I can't do much and when I try and do the tiniest thing I'm exhauted, like just having a shower or just getting dressed, my legs are bad, balance is bad, my lower back is sore all the time, sometimes can't hear well, get blurred vision, sometimes can't smell or taste much if anyone has had that, I never use to have pain but I do now all the time, I would just like something simple like a pill to help me and none of these scary treatments like needles and infusions and so on, please nomore pain!!
390	Apr 10, 2010 5:30 PM	Flu like side effects bad at first when injecting disease modifying drug. Concerned taking too many ibuprofen to combat the side effects
391	Apr 10, 2010 8:35 PM	MS Fatigue increasing relentlessly. Relapses are seriously worrying as you don't know if it will be permanent damage, how soon and when you recover. or how long the relapse will last.
392	Apr 10, 2010 10:23 PM	I worry about having to rely on the DMD more so the way it is administered at present and just how helpful it would be for me.
393	Apr 11, 2010 5:25 AM	i have been dignosed with ms for 13 years & recently had eurodynamics which showed up stress related bladder i dont understand this as wen i get urge to go to toilet i cannot get there without part or full leakage,i cannot hold my urine in at all,and because i havent got urgency the specialist will not perform bottox op on my

		bladder but maybe streaqtch bladder in my thoughts wouldnt this make my bladder worse as in not being able to hold urine
394	Apr 11, 2010 7:36 AM	I am only ever given steroids for ms flares and i hate the side effects of them.
395	Apr 11, 2010 9:44 AM	I am scared about the side effects of taking any drugs.
396	Apr 11, 2010 10:58 AM	Travelling abroad can be a concern with the need to carry additional items; find a fridge etc
397	Apr 11, 2010 12:49 PM	I started taking beta interferon 3 years ago and suffered 2 relapses, shoirtly afterwards. These relapses were disabling and I was unable to walk for 5-6 days. My GP prescribed steroids, at the latter of these attacks. I have been relapse free for over 2 years. I recently received vaccinations(5 months ago) prior to a holiday in Eygypt and unfortunately I have been unwell since. My MS symptons have all returned and are only now beginning to ease. I can still walk independently for a short distance, with regular and frequent breaks. Despite seeking medical advice prior to these vaccinations, when I was told it would be ok to take these vaccinations whilst receiving interferon, my body reacted badly both physically and mentally.
398	Apr 11, 2010 1:24 PM	I have persevered with the inconvenience of injections because the relapses would be worse. The injections require a bit of planning and some symptoms on the day of injection, but I feel this is worth suffering to minimise the likelihood of another relapse, and the inevitable worry and complete dependence on family to care for me that would result. A daily tablet, although also likely to have side effects, would be so much simpler. I also have needed to work from home on the day of the drugs delivery as there is no one to leave refrigerated drugs with, thus taxing my employer's patience since they do not really allow working from home. I am lucky that I am able to do this, since they respect the DDA.
399	Apr 11, 2010 1:57 PM	When I was on copaxone, my blood suagrs wwere not under control (Type 1 diabetic), when I spoke to the MS nurse and the Consultant that couldnt help me. It was only when i pushed that the MS nurse wrote to the drug comapny and they said that the absorption rates could be affected if both drugs were injected in the same area. i never injected insulin where I injected copaxone, but it was close, say at least 3 cms away. I dont inject insulin in my legs anymore and I came off copaxone becasue of this and also becasue my leges were so sore with lumps and swellings from the injections. I think that becasue my Neurologist doesnt know the answers to my questions and neither does the nurse, they are pretty useless and wheras I once had faith in them i now cosnider them to be superfluos to my requirements. there is no cure, there is no treatment, there is no hope.
400	Apr 11, 2010 5:15 PM	Sorry about my spelling, my ON has left me unable to see propeerly.
401	Apr 11, 2010 10:14 PM	I am very grateful that I get a disease-modifying drug. After managing pretty well for many years, my MS had started rapidly to worsen, with relapses happening every four months of so. I had to stop going into the office to work, though was fortunately able to continue to work, albeit for reduced hours, from home. I could see all to well if the progression had continued, I'd soon be unable to walk at all. These days I can still walk around the house (and have not yet been forced to move) and, on a good day, I might be able to walk some distance outdoors too. It's not much, and my life is very limited compared with how it used to be, but it's something. The interferon has stabilised the disease for now and, although some symptoms continue to worsen, I have not had a major relapse for several years now. If only it didn't mean sticking needles in myself...
		I am only recently diagnosed, and have not yet had the consultation at which we will discuss treatment options. However, as my impairment due to MS is still relatively mild, I'm concerned that the conventional self-injected or hospital-administered DMDs would have a greater impact on present quality of life than the symptoms of the

		disease itself. This may discourage me from accepting treatment. I think I would be much more open to the idea of treatment if I knew it would not involve relatively unpleasant modes of administration, such as injections or infusions.
402	Apr 12, 2010 6:48 AM	I have never been afraid of needles so the injhecting bit is only painful rather than frightening. I do suffer terribly from localised bruising at the site of the injection. They are painful and very unsightly. I cannot imagine the freedom and relief from these issues a pill would give me.
403	Apr 12, 2010 1:26 PM	Whilst i am grateful to be on DMD's, it is a burden to be injecting copaxone everyday
404	Apr 12, 2010 2:19 PM	Would love to have more freedom with the drugs as having to deal with the ms itself. Although injecting myself daily is not a buddle of fun I feel it is a small price to pay, in the absence of oral drugs, to keep any relapses to a minimum.
405	Apr 12, 2010 4:16 PM	I look forward to oral treatment being available in the near future.
406	Apr 12, 2010 4:57 PM	Have been lucky to have very few relapses and have only ever taken Amitryptiline.
407	Apr 13, 2010 7:20 AM	When having a relapse i am unable to inject myself due to not being able to hold the injection or grip. The tablet would help me as well as my family, as i am still able to take tablets on my own and not being a burden to others.
408	Apr 13, 2010 9:39 AM	I really haven't had a great experience of injecting. Avonex in particular but Copaxone has cause long waste of muscles and uneven skin. It also make it a lot harder to travel with these medications. I had a sarcoma in my thigh 4 years ago in the exact spot I often used to administer Rebif at the time (I did rotate the site but used my leg quite often as it was easiest to do myself). Although no doctors have said that the injection was the reason for the cancer, it seemed very coincidental that it was that exact location.
409	Apr 13, 2010 10:21 AM	Last week I had a very severe allergic reaction to Copaxone after injected, on both Tuesday and Wednesday nights, which caused an extremely itchy red rash over my entire body and face and made my lips, eyelids and throat swell up painfully. I have therefore now stopped taking Copaxone! My experience with Avonex lasted almost 3 years, the very first time I ever took it I said to my wife that ive been given the wrong drug it was that harsh. However I stuck with it the side effects never really stopped more I just got used to them, I used to dread Fridays as that was injection day. It took until Wednesday to recover then ied have Thursday then the whole thing would start again. Anyway after nearly 3 years I experienced exactly the same really harsh side effects as when I first took it I was at home alone and to be honest it really scared me, so I decided to stop taking it. Since ive stopped taking it I have taken a single Aspirin a day and a Krill oil supplement and although incredible small I have had more of a response to these than I ever did to Interferon, I had a repeat mri when I moved and my Neurologist
410	Apr 13, 2010 11:15 AM	has told me there is no active lesions, so ime sort of at a loss really yes I would take another medication preferably a pill but it has to show some sort of benefit as I am no lokger up for torture.
411	Apr 13,	The main issues with injecting daily is the skin site reactions, Lipoatrophy and getting

	2010 12:35 PM	help when injecting at sites that are hard to get to.
412	Apr 13, 2010 1:50 PM	when I have a relapse and receive IV steroids I always suffer sever side effects for 5-7 days post completion, followed by a slow recovery.
413	Apr 13, 2010 5:55 PM	HAving MS is like suddenly being drawn into running a life long marathon. Ok, so the challenge is on and it appears that for me there is no opting out. Having relapses along the way makes it more like an obstacle course or steeple chase. Having treatment or interventions that have side effects is like having to run uphill as well. I am blessed in having a family who cheer me on, who will even run alongside me and hold me up when I stumble ... and they would rather I ran as smooth a marathon as possible.
414	Apr 13, 2010 6:18 PM	I am certain that the drugs have stabilised my ms and have therefore improved the quality of my life.
415	Apr 13, 2010 6:41 PM	I am having a relapse at the moment and the reality of my illness taking over my life so much so that I cannot function without an immense amount of support from all those around me is very scary. I want to beat this illness, but know that there are times when I cannot. I know that I may soon need to start using disease modifying drugs, it has been discussed with my consultant, I have been put off by the method of administration.
416	Apr 13, 2010 7:21 PM	they make my body sore and red it hurts when injecting and i find it hard to do as i can never find a place on my arms legs or bum with enough fat and i have scars on my stomache so cant go there so overall a nightmare.
417	Apr 13, 2010 9:12 PM	Having only been diagnosed less than a year ago (and whilst encountering a trying 20m period in the run up to diagnosis) the fear of intravenously or self-injecting treatments has really put me off taking any dmd's. The taking of a pill for the condition would more likely satisfy the least level of change I feel I can cope with in dealing with this condition.
418	Apr 14, 2010 8:23 AM	I have had problems with my blood tests since taking Rebif. I have had continual problems with my liver function, although this has settled down, is still higher than the norm. The rebif has affected my thyroid function also. I am unsure that the Rebif is effective, as I have still experienced exacerbation of symptoms and mild relapses.
419	Apr 14, 2010 12:15 PM	Today is the best I will ever be as my condition deterates dialy. If it is safe, without major side effects and effect full I would clearly prefer daily pills, or better pills taken less than once a day, but they better be far more effective than interferon. It seems to be relative safe.
420	Apr 14, 2010 12:53 PM	By the way, I am a danish patient with MS, but I hope this survey could benefit MS patients in the hole of the EU
421	Apr 14, 2010 3:33 PM	in my opinion, having been diagnosed with ms is bad enough,having to take time out for to attend appointments for infusions, or having to have painful injections and feeling unwell afterwards,would not be my choice of treatment if i could take a wee pill every day!

Appendix D: Free text responses to an open question on people's main reasons for discontinuing the disease modifying drugs (Avonex, Betaferon, Extavia or Copaxone).

Number	Response Date	Response Text
1	Mar 26, 2010 9:19 AM	The Stress of injecting myself and did not seem to made a difference
2	Mar 26, 2010 9:38 AM	Injection site reactions
3	Mar 26, 2010 9:47 AM	Neurologist removed me as I kept forgetting to inject,
4	Mar 26, 2010 10:23 AM	there were a number of reasons from allergic reactions and hardened skin
5	Mar 26, 2010 10:24 AM	Side effects.
6	Mar 26, 2010 10:26 AM	Contraindicated by blood results - low white cell count and problem with liver. Also feeling low on Rebif.
7	Mar 26, 2010 10:44 AM	Rebif- i suffered scar tissue and many skin reaction sites
8	Mar 26, 2010 10:53 AM	It caused liver damage
9	Mar 26, 2010 11:27 AM	could not cope with self injection
10	Mar 26, 2010 12:07 PM	i developed a slight phobia of neddles and felt sick when i thought of taking my injection
11	Mar 26, 2010 12:07 PM	severe side effects
12	Mar 26, 2010 12:21 PM	Avonex , was getting too many relapses
13	Mar 26, 2010 12:28 PM	taken off it
14	Mar 26, 2010 12:47 PM	I moved from RRMS to Secondary Progressive
15	Mar 26, 2010 12:50 PM	Neurologist suspecting SPMS
16	Mar 26, 2010 12:51 PM	I couldn't inject myself, it was taking over everything else in my life !!
17	Mar 26, 2010 1:08 PM	I went from RRMS to secondary progressive

18	Mar 26, 2010 1:09 PM	side effects
19	Mar 26, 2010 1:13 PM	chage from copaxone to betaferon
20	Mar 26, 2010 1:37 PM	flu-like side effects
21	Mar 26, 2010 2:03 PM	undesirable side effects
22	Mar 26, 2010 3:14 PM	BETAFERON STARTED TO UPSET MY LIVER AND WAS TOLD BY DOCTOR TO STOP USING IT.
23	Mar 26, 2010 3:53 PM	Development on NAB's and increase in relapse rate
24	Mar 26, 2010 4:03 PM	Stopped Rebif as I was still relapsing twice a year, so after 2 years on it I was changed to Copaxone
25	Mar 26, 2010 4:23 PM	Allergy
26	Mar 26, 2010 4:46 PM	Side effects
27	Mar 26, 2010 5:05 PM	Side effects
28	Mar 26, 2010 5:07 PM	Had a severe bad reaction to it.
29	Mar 26, 2010 5:07 PM	Avonex left me with severe side affects.
30	Mar 26, 2010 5:16 PM	Felt generaly poorly. Aches,Stiffness,Depressed. Had two further relapses.
31	Mar 26, 2010 5:44 PM	side effects
32	Mar 26, 2010 5:49 PM	copaxone (5yrs) & rebif (3 yrs) had no effect
33	Mar 26, 2010 5:51 PM	Intolerance resulting in skin abcesses and lowering of white blood count
34	Mar 26, 2010 6:07 PM	I have recentley started taking Avonex but not been on it long enough to comment as yet.
35	Mar 26, 2010 6:15 PM	couldn't inject myself - despite hypnotherapy!
36	Mar 26, 2010 6:29 PM	I found the self injection too stressful. I could not come to terms with it having a deep fear of needles

37	Mar 26, 2010 6:31 PM	Drug worsened my crohns disease
38	Mar 26, 2010 6:32 PM	side effects (raised liver function)
39	Mar 26, 2010 6:33 PM	transferred to tysabri
40	Mar 26, 2010 7:00 PM	Consultants advise
41	Mar 26, 2010 7:03 PM	I started taken Tysabri (natalizumab)
42	Mar 26, 2010 7:03 PM	neutralising antibodies - Rebif
43	Mar 26, 2010 7:04 PM	Bad reactions to injection site, anxiety at having to inject
44	Mar 26, 2010 7:12 PM	sise affects of rebif unbearable i now take copaxone
45	Mar 26, 2010 7:12 PM	kept having relapses
46	Mar 26, 2010 7:41 PM	no impact
47	Mar 26, 2010 7:46 PM	Wanting to have a baby
48	Mar 26, 2010 7:47 PM	Cosultant felt that drug was no longer effective
49	Mar 26, 2010 7:58 PM	Avonex wiped my white cell, fatigue, suicidal
50	Mar 26, 2010 8:21 PM	side effects
51	Mar 26, 2010 8:41 PM	Fat atrophy at injection site
52	Mar 26, 2010 8:49 PM	NABs on Rebif
53	Mar 26, 2010 8:56 PM	antibodies in blood results meant a change needed to DMD
54	Mar 26, 2010 9:12 PM	reaction to inections
55	Mar 26, 2010 9:17 PM	Allergic reaction to Copaxone

56	Mar 26, 2010 9:23 PM	got on trial plus poor efficacy
57	Mar 26, 2010 9:52 PM	side effects
58	Mar 26, 2010 10:18 PM	MS nurse & consultant's advice
59	Mar 26, 2010 10:19 PM	I had more relapses, although short lived, whilst on Rebif than without it
60	Mar 26, 2010 11:40 PM	Consultant didn't think it was helping me- I agreed
61	Mar 27, 2010 12:22 AM	INCREASE IN RELAPSES AND NEW BRAIN LESIONS.
62	Mar 27, 2010 2:05 AM	liver funtion
63	Mar 27, 2010 7:50 AM	avonex was not very effective in controlling my relapses so i was transfered on to rebif 44mg.
64	Mar 27, 2010 8:08 AM	I took Rebif following participating in a trial for Cladrabine but it made me feel sick.
65	Mar 27, 2010 8:32 AM	it made me depressed
66	Mar 27, 2010 10:03 AM	Side effects
67	Mar 27, 2010 10:24 AM	Side effects and horror at self injection
68	Mar 27, 2010 10:47 AM	It was not stopping my relapses, caused me distress taking it. Now on Tysabri every four weeks.
69	Mar 27, 2010 10:51 AM	advised to stop due to blood abnormalities
70	Mar 27, 2010 11:40 AM	side effects
71	Mar 27, 2010 1:59 PM	rebif - causing more pain than helping. Reaction marks & stomach/bowel issues too painful to continure
72	Mar 27, 2010 2:06 PM	I hated the needle, the bruises and needle marks and the side effects
73	Mar 27, 2010 2:10 PM	extra pain with Copaxone
74	Mar 27, 2010 2:31 PM	Allergic reaction with Betaferon

75	Mar 27, 2010 2:35 PM	Rebif: had as many relapses per annum as not taking any drugs at all
76	Mar 27, 2010 3:41 PM	change from Betaferon to Rebif on hospital advice
77	Mar 27, 2010 4:01 PM	severe reaction to betaferon in my leg left me unable to walk.
78	Mar 27, 2010 4:08 PM	Neurologist agreed it wasn't helping
79	Mar 27, 2010 6:05 PM	side effects
80	Mar 27, 2010 6:13 PM	allergy to avonex
81	Mar 27, 2010 6:32 PM	I wanted to change to a drug that I only ad to take once a week.
82	Mar 27, 2010 7:28 PM	injection site ulcers
83	Mar 27, 2010 7:29 PM	NAB (Rebif)
84	Mar 27, 2010 7:42 PM	Had problems with my blood. Consultant decided to stop previous drug.
85	Mar 27, 2010 7:43 PM	Could not afford it and hated shots
86	Mar 27, 2010 8:10 PM	It affected my Kidneys.
87	Mar 27, 2010 9:26 PM	I had to inject and found this impossible because of pain and after effects etc
88	Mar 28, 2010 8:56 AM	It was far too painful.
89	Mar 28, 2010 10:05 AM	depression (Avonex)
90	Mar 28, 2010 12:35 PM	started tysabri
91	Mar 28, 2010 1:59 PM	Side Effects
92	Mar 28, 2010 3:31 PM	side effects and injection skin damage
93	Mar 28, 2010 4:11 PM	didn't work for me

94	Mar 28, 2010 4:31 PM	I didn't like giving myself the big injection (Avonex) once a week, I ended up injecting into my thigh bone by mistake and that WAS painful!!
95	Mar 28, 2010 5:33 PM	just on steroids for 5 days
96	Mar 28, 2010 5:54 PM	I developed a resistance to Avonex & no longer effective
97	Mar 28, 2010 5:57 PM	had a reaction to it
98	Mar 28, 2010 8:20 PM	was found to have more lesions and so started on Tysabri
99	Mar 28, 2010 8:21 PM	Was not working
100	Mar 29, 2010 3:26 AM	side effects
101	Mar 29, 2010 8:38 AM	trying for a baby
102	Mar 29, 2010 8:41 AM	My difficulties gradually stopped
103	Mar 29, 2010 10:10 AM	the side affects, and they did not reduce the relapse rates
104	Mar 29, 2010 10:13 AM	copaxone wasn't working for me and with rebif I was have severe site reactions
105	Mar 29, 2010 10:33 AM	bad reaction at injection sites
106	Mar 29, 2010 10:35 AM	I changed from Avonex, which did not seem to be working so well, to Rebif which it was thought would work better.
107	Mar 29, 2010 10:39 AM	side effects
108	Mar 29, 2010 10:52 AM	swollen ankles, injection site psoriasis
109	Mar 29, 2010 11:09 AM	injection site reactions on Rebif - inflammation on site & muscle athrophy, now on Avonex
110	Mar 29, 2010 11:09 AM	Negative reaction to medication
111	Mar 29, 2010 11:31 AM	ms worsened
112	Mar 29, 2010 11:43 AM	No longer effective in preventing relapses

113	Mar 29, 2010 12:01 PM	Increased relapse rate
114	Mar 29, 2010 12:19 PM	copaxone - skin site reactions were severe
115	Mar 29, 2010 1:30 PM	still getting regular relapses
116	Mar 29, 2010 2:23 PM	Disease progression
117	Mar 29, 2010 2:39 PM	Pain of injection sites, fat displacement,scarring, anxiousness of alternate day injections
118	Mar 29, 2010 2:52 PM	adverse reaction
119	Mar 29, 2010 3:30 PM	caused serious side effects
120	Mar 29, 2010 3:35 PM	I became secondary progressive and they didn't seem to have and benefit
121	Mar 29, 2010 3:55 PM	I FELT IT DID NOT SUIT ME AT THAT TIME (TRIAL MEDICATION)
122	Mar 29, 2010 6:11 PM	allergic to rebif,copaxone stopped working
123	Mar 29, 2010 7:39 PM	Disturbing post-injection side-effect
124	Mar 29, 2010 7:40 PM	Became Immune to Rebif and Copaxone side effects made my life extremely difficult and uncomfortable, more than the relapses.
125	Mar 29, 2010 7:41 PM	Rebif ,it was not working for me !!
126	Mar 29, 2010 7:50 PM	Iatrogenic hepatitis
127	Mar 29, 2010 7:59 PM	I was experience frequent relapses and reactions on the injection sites.
128	Mar 29, 2010 8:32 PM	side effects
129	Mar 29, 2010 10:18 PM	I took betaferon previously for two years and the side effects did not reduce I felt I had enough to contend with without the flew like symptoms .
130	Mar 30, 2010 1:45 AM	neutralizing antibiodies
131	Mar 30, 2010 2:09 AM	My Dr wanted to try something different to see if I would have fewer relapses

132	Mar 30, 2010 8:43 AM	Side effects
133	Mar 30, 2010 9:25 AM	Didnt seem to work and stop relapses
134	Mar 30, 2010 9:27 AM	Side effects
135	Mar 30, 2010 9:33 AM	condition improved after a course
136	Mar 30, 2010 9:39 AM	poor reactions to them
137	Mar 30, 2010 11:08 AM	Depression, mood swings.
138	Mar 30, 2010 12:39 PM	side effects
139	Mar 30, 2010 12:54 PM	I continued to have relapses on Rebif, roughly every 6 months
140	Mar 30, 2010 1:05 PM	They became neutralized in my body and ceased to work!
141	Mar 30, 2010 1:55 PM	side effects
142	Mar 30, 2010 2:33 PM	NAB +ve
143	Mar 30, 2010 2:35 PM	Horrendous side effects of Avonex
144	Mar 30, 2010 3:58 PM	continued relapsing and got fed up of injecting daily
145	Mar 30, 2010 4:05 PM	intensity in nerve pain
146	Mar 30, 2010 5:16 PM	on tysabri now
147	Mar 30, 2010 6:11 PM	not working
148	Mar 30, 2010 6:12 PM	rebif nearly killed me every time i took it
149	Mar 30, 2010 6:41 PM	flu like symptoms and painful injection sores
150	Mar 30, 2010 6:59 PM	side effect

151	Mar 31, 2010 2:15 AM	i used avonex for 2 years but could not cope with side effects, and changed to rebif
152	Mar 31, 2010 11:40 AM	started new drug tysabri
153	Mar 31, 2010 12:08 PM	advised by specialist
154	Mar 31, 2010 2:27 PM	Nurologist recommended stronger DMD because of relapse
155	Mar 31, 2010 2:58 PM	breathing problems with rebif
156	Mar 31, 2010 3:22 PM	Injection
157	Mar 31, 2010 3:26 PM	rebif no longer working. copaxone, site probs and disease progressing.
158	Mar 31, 2010 3:33 PM	the way my body reacted to them.
159	Mar 31, 2010 3:57 PM	medical advice that it was not effective
160	Mar 31, 2010 5:14 PM	Felt worse after injecting Rebif
161	Mar 31, 2010 6:55 PM	Tysabri - and pleased I changed...
162	Mar 31, 2010 7:32 PM	Side effects
163	Mar 31, 2010 8:57 PM	stress of self injecting
164	Mar 31, 2010 9:44 PM	Affected my liver
165	Mar 31, 2010 10:17 PM	Too painful and left bruises.
166	Mar 31, 2010 10:17 PM	Anxiety
167	Apr 1, 2010 12:36 AM	I hate needles and puncture marks, and I don't want to fill my body with toxins
168	Apr 1, 2010 8:07 AM	drug didnt work (betaferon)
169	Apr 1, 2010 8:49 AM	Having been re-assessed as having Secondary Progessive MS, the use of the drug would not have benifited me

170	Apr 1, 2010 9:31 AM	caused problems with my white blood cells and liver
171	Apr 1, 2010 9:58 AM	ms moved from RR to secondary progressive
172	Apr 1, 2010 10:59 AM	Didn't feel happy relying on drugs
173	Apr 1, 2010 11:06 AM	tried a new treatment that had no affect
174	Apr 1, 2010 11:09 AM	unacceptable side effects
175	Apr 1, 2010 11:54 AM	Copaxone wasnt working so well after 3 years
176	Apr 1, 2010 12:06 PM	was on avonex, had 3 relapses in year,started on tysabri a year ago
177	Apr 1, 2010 12:32 PM	x
178	Apr 1, 2010 12:51 PM	Problems with injecting myself
179	Apr 1, 2010 3:44 PM	Never got over the problems with injections and struggled with the "flu" symptoms - although had taken for around 4 years
180	Apr 1, 2010 4:12 PM	Side effects too debilitating for long term use
181	Apr 1, 2010 6:41 PM	It wasn't working, so I was put on Tysabri instead
182	Apr 1, 2010 7:58 PM	Kept relasping
183	Apr 1, 2010 8:14 PM	symptoms remained the same for 10 months
184	Apr 2, 2010 2:37 AM	Economic
185	Apr 2, 2010 8:39 AM	Relapses frequent on both avonex & copaxone. Now on tysabri.
186	Apr 2, 2010 10:33 AM	Betaferon, I had an allergic reaction and injection sites were extremely painful
187	Apr 2, 2010 2:37 PM	Over active thyroid, neurologist said I had to change from Rebif to Copaxone
188	Apr 2, 2010 5:05 PM	Was in Republic of Ireland taking Rebif. On return to UK was not then available to me.

189	Apr 2, 2010 6:31 PM	Had avonex, went to tasabri for 2 years and now on copaxone
190	Apr 2, 2010 7:41 PM	side effects i.e.one day a week of misery,for years
191	Apr 3, 2010 2:35 PM	I started taking tysabri as i was told rebif was not effective for me.
192	Apr 3, 2010 3:51 PM	I now have Tysbri infusions
193	Apr 3, 2010 4:32 PM	weight gain and depression
194	Apr 3, 2010 4:39 PM	betaferon did not seem to help me
195	Apr 3, 2010 7:55 PM	I developed bad reactions to copaxone after five years of few MS symptoms
196	Apr 3, 2010 9:19 PM	side effects and injection
197	Apr 4, 2010 8:57 AM	I was put on another treatment
198	Apr 4, 2010 10:37 AM	injected into a nerve
199	Apr 5, 2010 8:21 AM	ohne wirkung
200	Apr 5, 2010 10:32 AM	Side effects
201	Apr 5, 2010 11:27 AM	Stopped taking Avonex as it made mmy symotoms worse
202	Apr 5, 2010 12:26 PM	consultant changed drug
203	Apr 5, 2010 12:51 PM	ineffective
204	Apr 5, 2010 6:05 PM	My body started to reject the drugs
205	Apr 5, 2010 6:11 PM	i was advised by my medical team
206	Apr 5, 2010 8:25 PM	leg stiffness with avonex and rebif
207	Apr 5, 2010 8:35 PM	Made me sick

208	Apr 5, 2010 9:06 PM	avonex affected my mood & side effects & injection unpleasant
209	Apr 6, 2010 4:05 AM	side effects
210	Apr 6, 2010 9:57 AM	I was allergic to all of them
211	Apr 6, 2010 12:00 PM	I had a bad allergic reaction to Rebif, consultant took me off it.
212	Apr 6, 2010 1:25 PM	Pregnancy
213	Apr 6, 2010 5:17 PM	Lack of result and difficulty injecting regularly
214	Apr 6, 2010 5:51 PM	i did not like injecting and felt that it was nt working
215	Apr 6, 2010 6:30 PM	reacted badly to rebif
216	Apr 6, 2010 6:54 PM	side effects
217	Apr 6, 2010 7:27 PM	RRMS progressed to Aggressive RRMS so moved to Tysabri
218	Apr 6, 2010 8:42 PM	side affects(slow healing of skin areas) now poss due to diabetes
219	Apr 7, 2010 8:35 AM	Plateaued on Avonex - kept getting celulitis from Betaferon
220	Apr 7, 2010 11:25 AM	became needle phobic
221	Apr 7, 2010 11:53 AM	no longer able to tolerate side effects and skin tissue broke down
222	Apr 7, 2010 12:59 PM	Betaferon had lower percentage of relapse than Avonex
223	Apr 7, 2010 1:21 PM	My husband couldn't deal with giving me injections
224	Apr 7, 2010 2:37 PM	pregnancy
225	Apr 7, 2010 4:36 PM	I was taken Avonex for a year but it wasn't stopping relapses I'm now taking Tysabri and it been great no relapses in almost 2 years
226	Apr 7, 2010 6:16 PM	my ms was remiting replsing after 6 years my neurologist told me my ms has become secondery progresive so he stopped me from taking the drogs.

227	Apr 7, 2010 7:11 PM	Betaferon was no good for me because I have aggressive relapsing and remitting so I went onto Tysabri
228	Apr 7, 2010 8:29 PM	to begin tysabri
229	Apr 8, 2010 10:33 AM	self injecting
230	Apr 8, 2010 3:47 PM	continuing relapses - commenced on Tysabri
231	Apr 8, 2010 4:51 PM	stopped working
232	Apr 8, 2010 8:17 PM	side effects
233	Apr 9, 2010 12:05 AM	the flu like probs with this drug made me feel very ill.
234	Apr 9, 2010 5:59 AM	Ineffective and exacerbated my symptoms
235	Apr 9, 2010 10:16 AM	Developed neutralising anti-bodies
236	Apr 9, 2010 10:23 AM	MS NOW PROGRESSIVE NOT RR & HAVE BEEN ON FOR 5 YEARS
237	Apr 9, 2010 10:37 AM	skin reactions
238	Apr 9, 2010 11:04 AM	didn't seem to work and had site reactions
239	Apr 9, 2010 11:43 AM	did not work
240	Apr 9, 2010 11:45 AM	I now recieve Tysabri
241	Apr 9, 2010 12:55 PM	severe reactions to avonex and copaxone
242	Apr 9, 2010 2:26 PM	decision of dr
243	Apr 9, 2010 2:43 PM	Felt it had stopped working after nearly 4 years!
244	Apr 9, 2010 3:05 PM	avonex-due to mood problems copaxone-skin problems. Also I did not really believe I had MS.
245	Apr 9, 2010 4:01 PM	Rebif did not suit me ; made me so ill

246	Apr 9, 2010 5:56 PM	I got very painful site reactions and had panic attacks
247	Apr 10, 2010 10:03 AM	stopped working & alot of relapses
248	Apr 10, 2010 11:21 AM	severe side effects
249	Apr 10, 2010 11:54 AM	Reb/Cop - bad inj site reactions, distress of self-injecting
250	Apr 10, 2010 1:41 PM	all had adverse effects but currently on mitoxantrone
251	Apr 10, 2010 5:04 PM	did'nt agree with me at all
252	Apr 11, 2010 1:49 PM	Cpaxone interfeered with insulin absorption, Avonex made me feel so ill for 2 days a week even after being on it for 12 months
253	Apr 11, 2010 2:28 PM	more side effects from Rebif. changed to Avonex only 1 injection a week instead of 3 with Rebif , less side effects with Avonex.
254	Apr 11, 2010 4:42 PM	my consultant felt I needed "stronger" dose
255	Apr 11, 2010 4:57 PM	Avonex - Very low white cell count - now on Cop.
256	Apr 12, 2010 11:38 AM	I could not tolerate the side effects after 9 months of use
257	Apr 12, 2010 2:11 PM	frequency of relapses
258	Apr 12, 2010 4:10 PM	Relapses increased not decreased
259	Apr 12, 2010 6:31 PM	was told that it was no good for me .
260	Apr 12, 2010 6:46 PM	I am now receiving tysabri
261	Apr 12, 2010 7:16 PM	Bad reaction
262	Apr 12, 2010 10:51 PM	too many relapses on 1 affecting my liver on other 1
263	Apr 13, 2010 8:46 AM	capaxone - not effective (enough)
264	Apr 13, 2010 9:32 AM	Scan still showed activity, didn't lessen relapses, needles cause indentations in my skin

265	Apr 13, 2010 10:15 AM	Flu-like symptoms of Rebif were intolerable, had severe, dangerous allergic reaction to Copaxone
266	Apr 13, 2010 11:04 AM	skin reactions, joint pain, actual injecting itself
267	Apr 13, 2010 12:01 PM	developed antibodies to rebif
268	Apr 13, 2010 1:42 PM	Copaxone discontinued due to reaction to my skin
269	Apr 13, 2010 5:44 PM	Side effects horrendous - worse than MS symptoms
270	Apr 13, 2010 7:12 PM	i became allergic to copaxone i could not walk my legs doubled in size
271	Apr 14, 2010 12:46 PM	Started taking Tysabri instead
272	Apr 14, 2010 2:33 PM	i was on copaxone and had 2 flare ups a year and had site discomfort

Appendix E: Free text responses to an open question on people's main reasons for discontinuing Tysabri.

Number	Response Date	Response Text
1	Mar 28, 2010 12:37 PM	wanting to start a family
2	Mar 30, 2010 1:06 PM	I became allergic to it.
3	Apr 1, 2010 11:10 AM	doctors decision
4	Apr 2, 2010 6:33 PM	consultant was worried about further complications after 18 months of use
5	Apr 2, 2010 7:44 PM	fear of possibility of brain virus after 2 years
6	Apr 5, 2010 10:35 AM	Side effects
7	Apr 7, 2010 8:38 AM	fear of pml
8	Apr 8, 2010 4:54 PM	didn't work
9	Apr 10, 2010 1:42 PM	side effects so bad
10	Apr 12, 2010 6:35 PM	was told it was no good for me.

Appendix D - <u>Interview questions sent to the patient expert in advance of the interview</u>

Life with MS

1. When were you diagnosed with MS?

2. How did your diagnosis for MS come about and how long did your diagnosis take?

3. What was your life like before your diagnosis e.g. work, family, lifestyle, socially?

4. Before alemtuzumab what was it like to live with MS? What impact did it have on your life and your family/carer? Physically, mentally, socially etc

5. How often were you experiencing relapses?

6. What symptoms have you/did you experience as a result of your MS?

7. Did you need support from your family members and if so, how much support did you need? More so than if you didn't have MS?

8. What treatments were you taking for your MS? How long had you been taking them?

Alemtuzumab and the trial

9. How did you find out about alemtuzumab and the trial? What information were you given about the drug and the trial?

10. When did you start taking alemtuzumab?

11. Were you aware of any risks associated with alemtuzumab? If so, did this change your willingness to take part in the trial? Were you confident that the benefits of the treatment would outweigh the associated risks?

12. What expectations did you have about the impact that alemtuzumab would have on your life given what you were told about the treatment? What benefits or outcomes did you hope to gain from the new treatment? What was most important to you e.g. reduction in relapses and in symptoms, improvement in physical disability etc

13. Did you experience any side-effects as a result of alemtuzumab? If so, what were they and were they tolerable/treated?

14. Which symptoms specifically do you notice improvement with when taking alemtuzumab?

Life after alemtuzumab

15. In terms of the relapses, how does that compare with when you were first diagnosed and the period without being on the drug?

16. In terms of the affect on your day to day life, what sort of activities has alemtuzumab allowed you to do? How has it made a difference to your physical well-being?

17. Do you find you need as much support from families/friends/carers or has it changed since taking alemtuzmab? Increased? Decreased?

Care and support

18. Were you put in touch with an MS specialist nurse in your area? If so, was the contact regular?

19. How often did you see your neurologist before/during the trial?

20. Was/is your care coordinated and by whom?

21. What specialist care did you have access to before/during trial e.g. physiotherapist, continence, occupational, emotional support etc?

The wider picture

22. Looking at the wider picture, so not specifically related to you but to patients with MS more generally, what do you think the differences would be for those people if alemtuzumab was made available on the NHS?

23. Conversely, so what do you think the implications would be if alemtuzumab was not actually approved by NICE? And not made available?