My MS My Symptoms

People with MS' experiences of cannabis and symptom management strategies

Findings from the 2014 symptom management survey on Sativex and cannabis

Diane Redfern -Tofts

Let's stop MS **together**

Contents

Executive Summary

Anecdotal evidence suggests that in the absence of access to Sativex some people with MS have tried using cannabis in other forms to manage their symptoms.

The research presented in this report provides a detailed exploration of cannabis use by people with MS in the UK trying to manage their symptoms, gathered through an online questionnaire.

Reasons people are using cannabis to try to manage symptoms

56% of those currently using cannabis reported that it was because they felt that the benefits outweighed the side effects. Many believed it to be a natural remedy and more effective than licensed treatments.

For many, cannabis seemed like the only available option. 40% of those using cannabis reported that they were doing so completely because they were not able to access licensed treatments for the symptoms of their MS.

Using cannabis to try to manage symptoms

22% of people surveyed had used cannabis to try to manage the symptoms of their MS.

Furthermore 48% of the people who had never used cannabis to manage their MS symptoms said that the idea had crossed their mind.

Some explained that they were concerned about prosecution, but would use cannabis to manage their symptoms if it was legal.

Thoughts about legalisation

72% of people with MS believe that medicinal cannabis should be legalised.

One in five people felt that the legalisation of medicinal cannabis was currently either high priority or essential for them.

Each person with MS has different symptoms, opinions and experiences of treatments and develops different coping strategies. Therefore how someone deals with their symptoms is highly individualised and can result in multiple treatments and self-management strategies. Making decisions about treatment are inescapably difficult and complex, and this is complicated further when struggling to access a treatment. Many people were frustrated that they had to fight for the medication that has the potential to help them. People stated that they should be able to get the right treatment at the right time.

Many people with MS have used cannabis to try to manage their symptoms and feel that they should be able to make this decision ‘without a fear of prosecution’.

Introduction

MS is an unpredictable fluctuating condition. People with MS experience a wide variety of symptoms that can be influenced by many different factors such as stress, fatigue and heat. 'My MS My Needs 2016: access to treatment and health care' revealed that around two percent of people with MS are accessing Fampyra or Sativex across the UK,[1] two treatments that are proven to significantly improve the quality of life for people with MS. They can help people walk more easily and manage painful muscle spasms but there is growing concern that access to these treatments is only going to become more difficult.

In October 2014 the National Institute for Health and Care Excellence (NICE) published clinical guidelines for the treatment of MS. The guideline rejects Fampyra and Sativex as treatment options on the grounds of being too expensive.[2]. The MS Society disputes the method by which NICE reached its conclusions, and believes that NICE's decision to reject the treatments was based on a flawed assessment and inappropriate process. We want to see a full assessment of these medicines that is more thorough and robust than the clinical guideline process, because more evidence can be submitted by a wider group of people.

For more information on the range of symptom management treatments available for MS please see the MS Society website www.mssociety.org.uk or call 0808 800 8000.

The MS Society called for people with MS in 2014 to send in their experiences of trying to access Sativex (nabiximols), which is a cannabis-based oral spray licensed for treating spasticity in people with MS. These responses indicated that our information on the use of Sativex was sparse and demonstrated a need for us to find out more about the views and experiences of people with MS. Some people stated that in the absence of access to Sativex, they used cannabis (marijuana) to relieve their symptoms and we found that information held by the MS Society on the use of cannabis (marijuana) was inadequate and we wanted to find out more about what people with MS think.

The research presented here is part of our work to understand these issues more clearly.

The initial results of the research project exploring experiences of Sativex can be found in the report 'Managing MS, Managing Spasticity: People with MS' experiences of Sativex[3]'. The findings presented here focus on experiences of cannabis.

---

[1] Redfern-Tofts, D., Wallace, L. and McDougal, A. (2016) My MS My Needs 2016: access to treatment and health care. Technical report

2 Sativex is technically available in Wales on the NHS as decisions are taken by a separate body, although we have evidence that many people with MS in Wales do not actually receive it. MS Society Cymru is working with the Welsh Government and Local Health Boards and we expect to see a rise in the number of prescriptions for Sativex in Wales.

[3] Redfern-Tofts, D (2014) Managing MS, Managing Spasticity: People with MS' experiences of Sativex

Method

Questionnaire design

An online questionnaire was designed by the MS Society's Policy and Research teams to explore the use of Sativex and cannabis as a way people with MS may try to manage their symptoms. The questionnaire included both quantitative and qualitative questions. Qualitative responses are provided in this report using pseudonyms.

The questionnaire's nature meant that the number of items varied depending on how people answered specific questions. All respondents answered the initial nine items; focusing on demographics, year of diagnosis, symptoms experienced and awareness of Sativex (nabiximols).

The main part of the questionnaire was then divided into two sections; one on Sativex and the other on cannabis. This report focuses on the responses received to the second part of the questionnaire on cannabis. The results from the first part are available in the report 'Managing MS, Managing Spasticity: People with MS' experiences of Sativex'[4].

The respondents fit in one of three categories, meaning the section about cannabis was thus split into three main branches:

- Branch 1 – For those who had never used cannabis, but had considered using it
- Branch 2 – For those who had previously used cannabis, but were not at the time of completing the questionnaire
- Branch 3 – For those who were currently using cannabis

All respondents from these three branches were asked about the reasons behind their decision. Branches 2 and 3 also included items about the symptoms that they were using cannabis to try to manage.

The questionnaire was piloted with MS Society Research Network members (people affected by MS), who assessed any necessary design and content changes (question wording, topic and structure). See appendix 1 for a full list of questionnaire items.

Respondents

The questionnaire was promoted in three different ways between 8 and 22 September 2014:

1. MS Society social media channels
2. MS Society Campaigns Community
3. UK MS Register

A total of 5199 people responded to the questionnaire. The data from 1205 people was not included in the analysis for a variety of reasons:

- Partial responses (n=958)
- Disqualification due to not having a diagnosis of MS, not living in the UK, or being under the age of 18 (n=247)

Data from the remaining 3994 people who completed the questionnaire was used for analysis.

---

[4] Redfern-Tofts, D (2014) Managing MS, Managing Spasticity: People with MS' experiences of Sativex

Demographics

3,994 people completed the questionnaire, 71% (n=2852) females and 29% (n=1142) males. Figure 1 shows that most of the respondents (51%) were aged between 35 and 54 years. Figure 2 shows that the majority of people (49%) had relapsing remitting MS or secondary progressive MS (28%).

Figure 1: Breakdown of the age of respondents

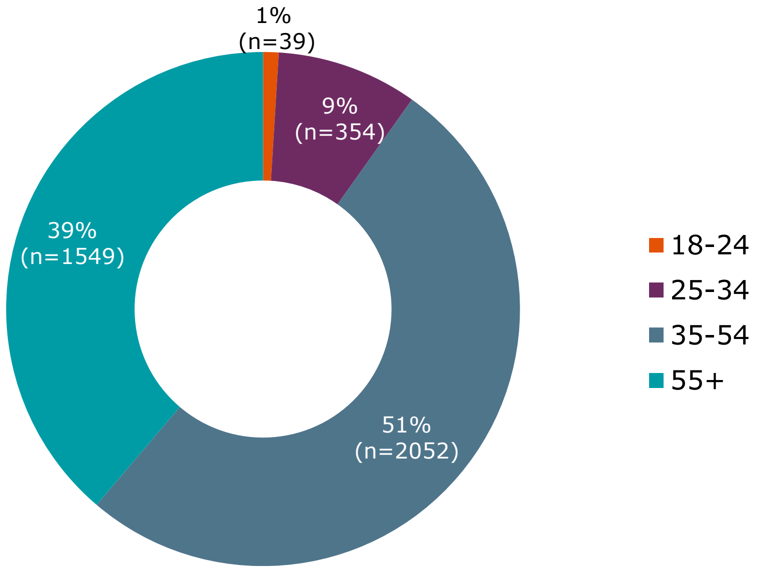


Figure 2: Breakdown of the type of MS

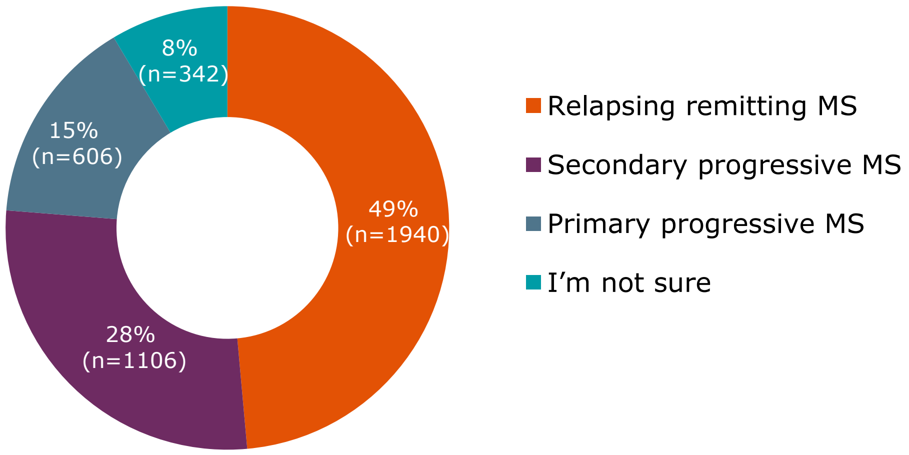
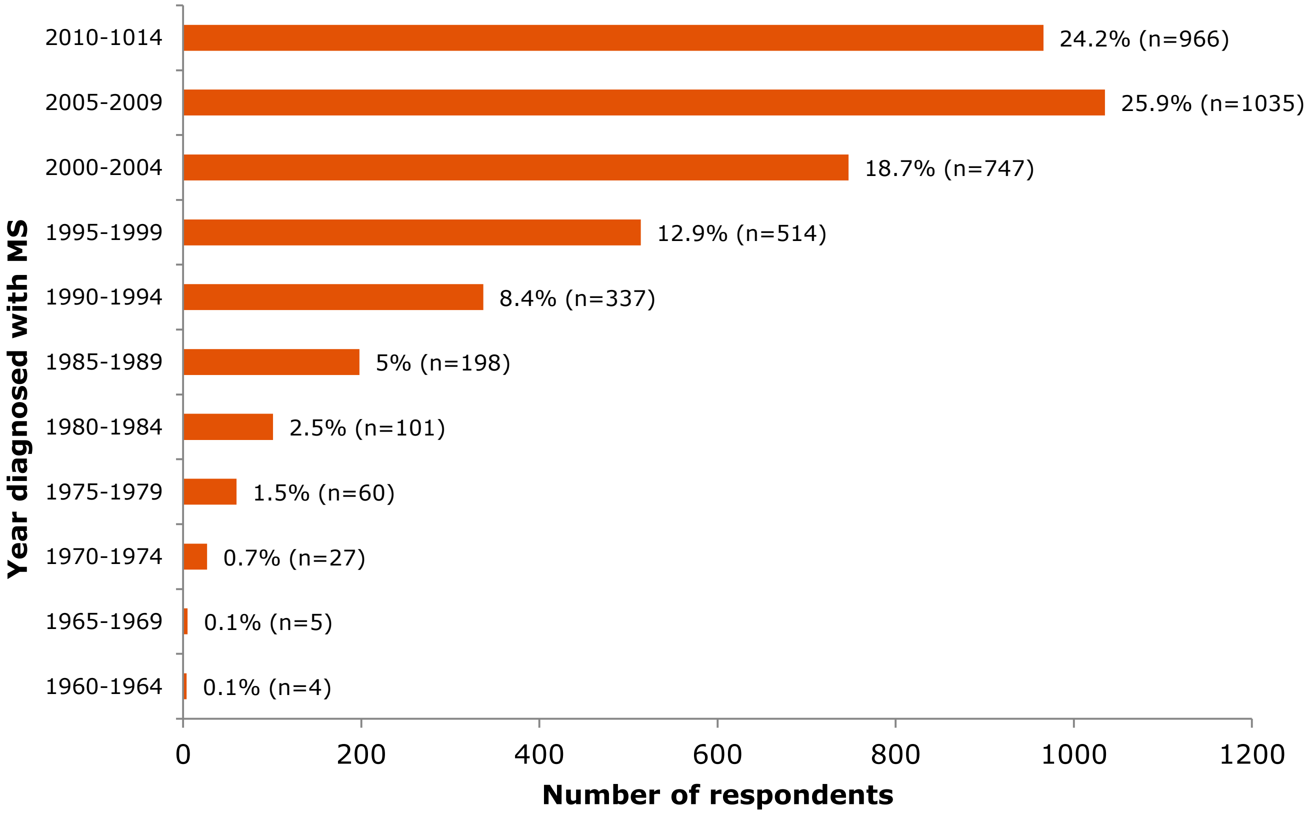


Figure 3 below shows that 26% (n=1035) of people in the sample were diagnosed with MS between 2005 and 2009.

Figure 3: Breakdown of when respondents were diagnosed with MS



Cannabis – a summary of findings

Legalising medicinal cannabis

All respondents were asked whether in their opinion medicinal cannabis should be legalised.

Figure 4: Breakdown of whether respondents think that medicinal cannabis should be legalised

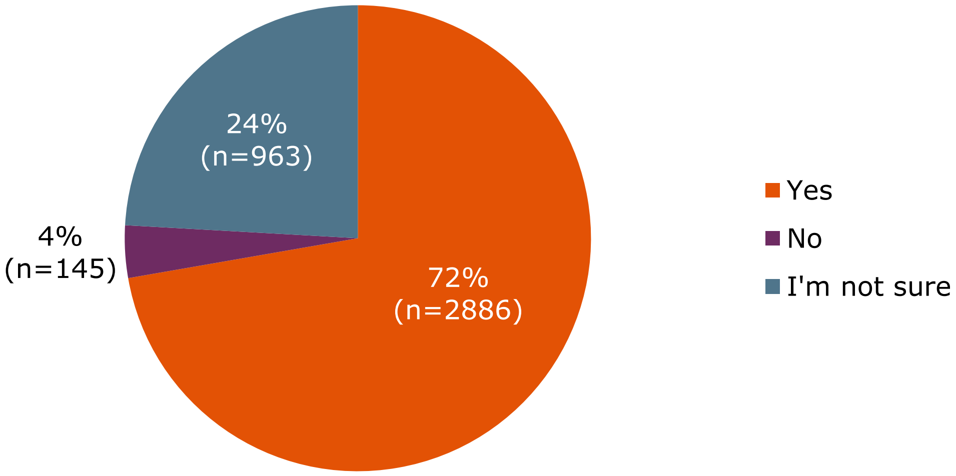
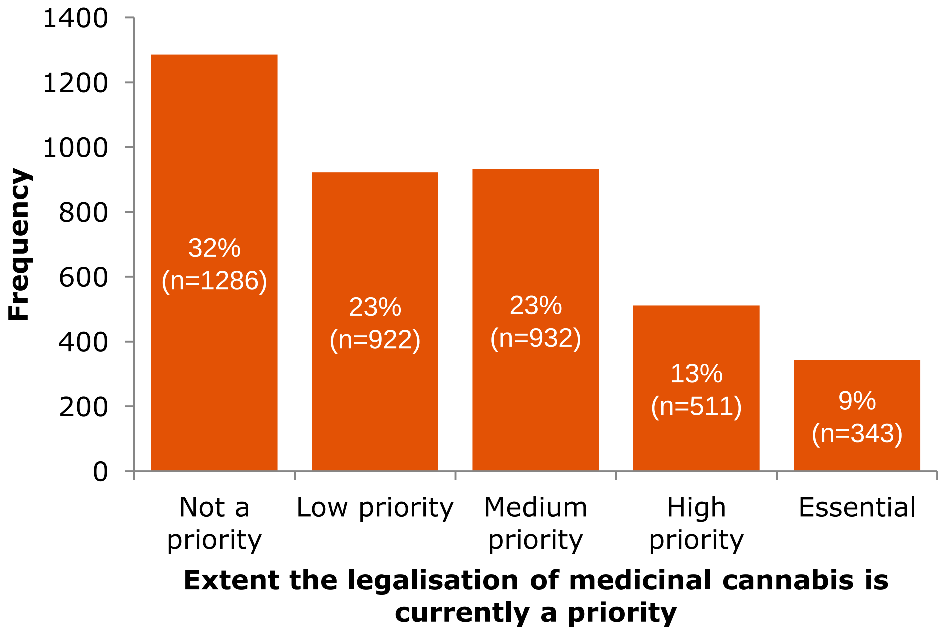


Figure 4 shows that 72% (n=2886) of respondents believed that medicinal cannabis should be legalised.

24% (n=963) were not sure about whether it should be legalised and 4% (n=145) believed that medicinal cannabis should remain illegal.

All respondents were also asked to what extent the legalisation of medicinal cannabis is a priority for them currently.

Figure 5: Extent to which the legalisation of medicinal cannabis is currently a priority for respondents



32% (n=1286) of respondents reported that the legalisation of medicinal cannabis is not a priority for them at present.

However for 22% (n=854) of people the legalisation of medicinal cannabis was currently either a high priority or essential.

Experience of cannabis

There were five different experiences of cannabis captured in the questionnaire.

Those who:

1. had never thought about using cannabis
2. had never used cannabis, but the thought had crossed their mind
3. had never used cannabis, but had considered it and weighed up the pros and cons
4. had previously used cannabis, but were not at the time of completing the questionnaire
5. currently used cannabis

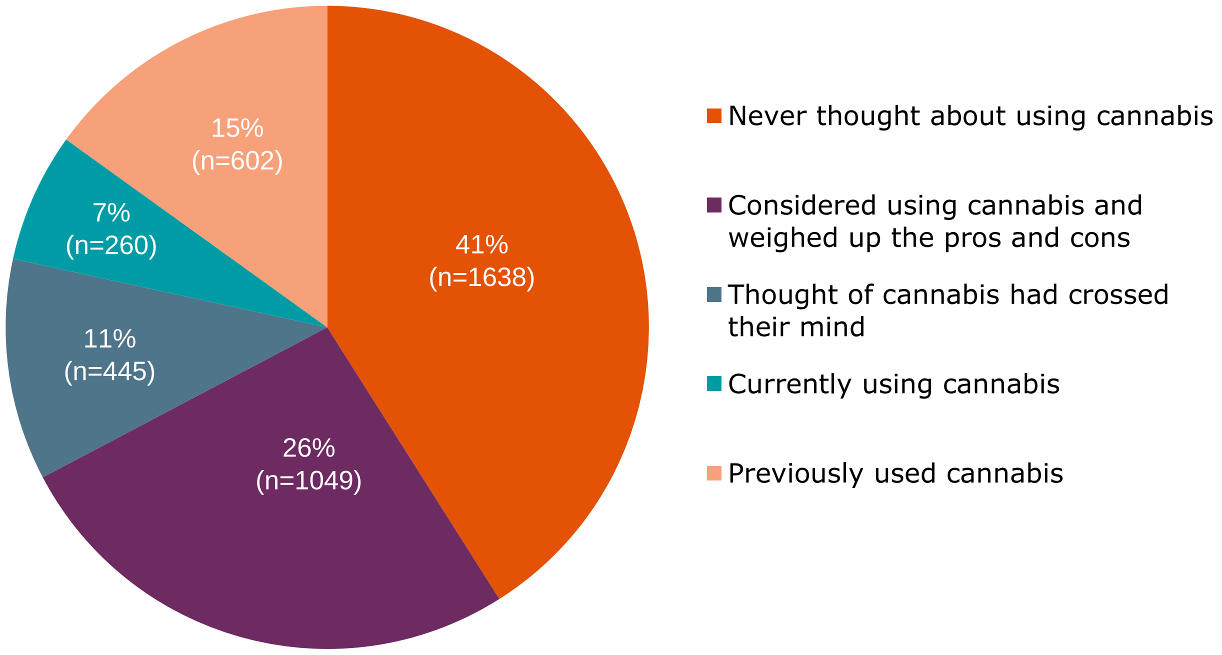
All respondents were asked whether they have ever used cannabis to try to manage the symptoms of their MS.

Figure 6 indicates that 22% (n=862) of respondents have used cannabis to try to manage the symptoms of their MS at some point. With 7% (n=260) of people still using cannabis at the time of completing the questionnaire. 78% (n=3132) of respondents had never used cannabis to try to manage the symptoms of their MS.

11% (n=445) of respondents reported that they had thought about using cannabis i.e. it had crossed their mind and 26% (n=1049) reported that they had weighed up the pros and cons of using cannabis to try to manage the symptoms of their MS.

When looking only at the 78% (n=3132) of respondents who had never used cannabis 48% (n=1494) had thought about it.

Figure 6: Experience of cannabis as a way of trying to manage MS symptoms



Those who had never thought about using cannabis or the thought had only crossed their mind were not asked any further questions about cannabis. The remainder of this report presents the data gathered in relation to experience of groups 3, 4 and 5 above.

Group 3 - Never used cannabis but had considered it

This section of the report focuses on the 26% (n=1049) of respondents who have never used cannabis to try to manage the symptoms of their MS, but have seriously considered it and weighed up the pros and cons.

Table1 shows the reasons why those who had considered using cannabis had not tried it. 26% (n=273) of people reported that concern about prosecution was the reason they had not tried using cannabis, 22% (n=226) said that it was because they want to manage their MS without taking illegal drugs and 18% (n=188) stated that it was because they do not agree with using any illegal drugs.
The belief that cannabis would not help their symptoms was not at all a factor in the decision for 43% (n=447) of people and 25% (n=265) of respondents reported that concern about potential side effects was not at all a factor in the decision not to use cannabis.

Table 1: Reasons respondents who had considered using cannabis to try to manage the symptoms of their MS have not

Reasons never used cannabis	Not at all	To a small extent	Somewhat	To a large extent	Completely	Total answered
Believe it would not help symptoms	43% (n=447)	24% (n=249)	22% (n=232)	8% (n=88)	3% (n=33)	100% (n=1049)
Concern about potential side effects	25% (n=265)	25% (n=266)	21% (n=219)	19% (n=199)	10% (n=100)	100% (n=1049)
Breastfeeding, pregnant or trying to conceive	71% (n=740)	0 (n=1)	0 (-)	0.4% (n=4)	1% (n=10)	72%(n=755)
A specific medical issue meant it was not suitable	87% (n=916)	5% (n=48)	5% (n=50)	1% (n=15)	2% (n=20)	100% (n=1049)
Want to manage MS without drugs	56% (n=586)	16% (n=169)	16% (n=163)	7% (n=71)	6% (n=60)	100% (n=1049)
Want to manage MS without taking illegal drugs	31% (n=321)	17% (n=181)	15% (n=153)	16% (n=168)	22% (n=226)	100% (n=1049)
Do not agree with using any illegal drugs	36% (n=374)	19% (n=203)	15% (n=154)	12% (n=130)	18% (n=188)	100% (n=1049)
The financial cost	35% (n=371)	16% (n=167)	20% (n=212)	16% (n=165)	13% (n=134)	100% (n=1049)
Concern about prosecution	23% (n=236)	16% (n=167)	16% (n=168)	20% (n=205)	26% (n=273)	100% (n=1049)

In order to understand in more depth why some respondents had never used cannabis, they had the opportunity to provide further details of their reasoning in the questionnaire. This section of the report presents analysis of the two themes generated from their responses; criminalisation of cannabis users and considerations about cannabis.

Criminalisation of cannabis users

A large amount of the data related to the use of cannabis as a criminal act. The following three sub-themes were generated as a result of the thematic analysis:

1. Accessing cannabis
2. Safety
3. Moral concerns

Accessing cannabis

The majority of comments about reasons for not using cannabis were about not knowing how or where to access the drug, as well as the impact this could have on family and friends.

Many respondents explained that they were not using cannabis to try to manage the symptoms of their MS because they simply 'don't know where to get it'. Such as Mark who stated that he has 'no idea how to get hold of it as [he has] never used illegal drugs'.

For others accessing cannabis was a logistical issue, as they were unable to leave the house or could only go outside with someone else present. Danielle 'cannot leave the house alone, and [doesn't] know anyone who could get hold of some' and Craig said 'I wouldn't be able to go out and get it…You can hardly have it delivered to your door like a grocery order'.

There was a concern for some that by using cannabis they would be putting the people close to them at risk. For example, Ron wrote that he is 'housebound and would not like anyone else having to take the risk of getting it for [him] illegally' and Jane reported that she was not using cannabis because she does not 'know how to get some without putting a friend at risk of prosecution'.

Others explained that they were highly concerned that using cannabis could have a negative impact on their family. Chris explained that she is 'concerned about potential prosecution/ problems for [her] husband, friends and family' and Daniel stated:

> 'I don't fancy being caught out in the streets buying marijuana. It would only mean my face and personal things being written about me in the local newspaper. I'm not scared, i.e. I mean if I knew where to get it, it wouldn't be the prosecution that would bother me. It would be me and my family's name being dragged through the mud'.

Others felt that using an illegal drug would not be seen as setting a 'good example' for their children. These respondents explained how they did not want their children to use illegal drugs and were worried that using cannabis themselves could somewhat undermine this. For some the impact being a cannabis user could have on their family's career was the deciding factor:

> ‘My husband is a member of the police force. The consequences of me being found with illegal drugs no matter how beneficial will be disastrous for the family. Therefore I have no option but to refuse illegal drugs’.

> ‘I can’t because I’m married to a Police Officer or I probably would’.

A small number of people explained that they had not used cannabis because of the effect it could have on their own career. Those who work in security, the medical profession and in education were particularly concerned about the ‘risks to [their] career’. Liz ‘turned it down on the basis of the implications it might have at work if anyone were to ask and not because [she] wasn’t prepared to try it’. So, many people explained that they were unable to try cannabis to manage the symptoms of their MS, because of the implications of taking an illegal drug. Some respondents did explain that a lack of access to Sativex would mean that they would be more likely to use cannabis despite this.

> ‘My main concerns are prosecution, having to find a ‘dealer’, the ‘high’ you get from cannabis and becoming hooked. If Sativex is withdrawn I WILL risk all of these things to get cannabis!!! At least with Sativex you don’t get high or hooked’.

> ‘I already have access to Sativex, if it was taken away I would be forced to acquire cannabis and as a result break the law which I am extremely worried about but I would have no choice’.

Safety

A further factor that seemed to be integral to people’s decisions not to use cannabis involved the lack of safety related to using an illegal drug. This included both ‘the uncertainty of what you are actually buying’ as well as the places that people would have to go to buy the drug.

It was noted by many that ‘it is not regulated so there is a quality control issue that puts a user at risk’. Buying cannabis means that there is ‘no guidance on dosage’, no way of medically managing the side effects or monitoring interactions with other drugs. These issues were given by many people as strongly influencing their decision not to use cannabis.

> ‘Cannabis available through non legitimate avenues is not regulated, can’t be relied upon to be totally safe, is not a route I would wish to go down’.

> ‘AND most importantly, the quality of any ‘off the street’ products is unknown, not guaranteed to be reproducible quality, and could be ‘cut’ with other dubious products’

Many of the people who gave quality as a reason for not using cannabis stated that they ‘would like to try it from a safe and legal source’.

Moral concerns

It was evident that some questioned the morality of cannabis use and reported that they were generally ‘anti drugs’.

Respondents explained that they were not using cannabis for a number of 'moral concerns'. For example Sophie stated that she 'dislike[s] the suffering of victims of the drug trade (dealers' brainwashed mules)' and Sarah explained that she doesn't 'want to fund organised crime by using it'.

Overall people were reluctant 'to do business with drug dealers' or 'become involved with the illegal drug culture'.

Ultimately the reason many people have not used cannabis to try to manage their MS is exemplified in Henry's statement:

> 'I just do not agree with putting myself in the position of being a criminal'

So for many the criminalisation of cannabis users was heavily involved in their decision.

Considerations about cannabis

The following four sub-themes were generated:

1. Progression of symptoms
2. Side effects
3. Prior experiences
4. Healthcare professionals

Progression of symptoms

Many people who had never used cannabis explained that they may do so in the future if their symptoms worsen. Respondents made comments such as 'Don't need it yet', 'I don't feel that my symptoms have got to the level where I would wish to try it' and 'I would certainly consider it if my symptoms progressed and I thought it would help'.

Side effects

The potential side effects of cannabis use were discussed by many people as being integral to their decision not to use it. Some people were concerned that they may become 'addicted to it' and the prospect of 'losing control' was the reason for others.

Danny noted 'I don't like the feeling of not being in control, which I think cannabis would do' and Melissa, who experiences cognitive problems, does 'not want to be a zombie'. She is concerned that using cannabis may cause her cognitive difficulties to worsen and explained that she does 'not like losing control'. Emma also believes it will make her 'more unsteady and have less control'.

For many it was the 'potential psychological side effects' that were the main concern. Julie who had a career in nursing within psychiatry explained that she 'fear[s] the long term effects' of cannabis. Other respondents expressed that they were 'concerned about how it affects and causes mental disorders'.

> 'My mind is one of the few parts of my body that functions normally – I am very reluctant to take anything that might impair my ability to think clearly'

There was also a feeling that it may make ‘fatigue and mental confusion worse’, and Jason was ‘Scared that it would affect [his] almost non-existent balance and/or make [him] feel dizzy’.

Prior experiences

Others wrote about how witnessing other people using cannabis had made them reluctant to take it themselves. Fiona stated ‘Too many times I have seen the way this rubbish has messed about with a smoker’s brain’ and Nicola has ‘seen too many friends who consume regularly and have mental health issues’.

> ‘It just doesn’t feel right. I don’t like anything that alters who I am. I’d rather still be me with the pain than be pain free but no longer myself inside’.

Many people had used cannabis recreationally and not as a way of trying to manage the symptoms of their MS. For some it was these experiences that meant that they had not tried it as a way of managing their symptoms. For example Georgie had used cannabis before diagnosis and was ‘frightened to go back to those days’. Respondents explained that they had taken it recreationally and ‘didn’t like the effects it caused’, such as Callum who found that smoking it made him ‘quite paranoid’. Grace wrote ‘smoking marijuana makes me forget where I am and what I am doing’.

Some people, who used cannabis prior to being diagnosed with MS, wondered whether they were essentially ‘self-medicating’. Ian stated:

> ‘Spent 18 years using recreationally, sometimes heavily. My MS developed a month after I stopped smoking it. I have often wondered whether I had self-medicated and kept the condition at bay until then’

Many people who used cannabis in the past had explained that they were not currently using it as they were worried that they may develop an addiction. Ellie does ‘not want to start smoking again having given up the habit since 1982’.

Healthcare professionals

Some people wrote about discussions with healthcare professionals about using cannabis. In some cases they seemed to be relatively positive about the potential benefits. Such as Dean’s GP who advised him ‘of the benefits of cannabis’, and Charlotte’s doctor who said ‘she would not blame’ her for considering cannabis and that ‘it would help the pain’. Georgina was asked by her MS nurse whether she had tried it and this has led her to think ‘it’s worth a shot’.

However, other people who raised the subject with their neurologist were advised against it. In some cases they ‘felt the drugs available were more beneficial’ or that ‘it would be unwise’ due to previous psychological issues.

Summarising the decision not to use cannabis

- Many people wrote about how they would be likely try cannabis if it was not illegal and that they were concerned about prosecution.
- Gaining access to cannabis was not possible for many and the fact that cannabis is not monitored or regulated like legal drugs means that safety is a major concern.
- The side effects of cannabis use were discussed by many people and previous experience of the drug was a deterrent for some.

Group 4- Previously used cannabis

This section will specifically focus on the 15% (n=602) of respondents who have previously used cannabis to try to manage the symptoms of their MS but were not using it at the time of filling out the questionnaire. The table below shows that the main reason respondents stopped using cannabis was because they wanted to manage their MS without taking illegal drugs. 18% (n=111) stated that this was completely the case. 15% (n=90) of people stopped using cannabis because they were concerned about prosecution and 12% (n=71) said that it was completely due to the side effects that they were experiencing.

Table 2: Reasons respondents stopped using cannabis

Reasons stopped using cannabis	Not at all	To a small extent	Somewhat	To a large extent	Completely	Total answered
Believed it was not helping symptoms	55% (n=332)	14% (n=84)	13% (n=78)	8% (n=45)	11% (n=63)	100% (n=602)
Side effects being experienced	56% (n=336)	12% (n=74)	10% (n=58)	11% (n=63)	12% (n=71)	100% (n=602)
Concern about potential side effects	58% (n=346)	15% (n=87)	12% (n=73)	8% (n=50)	8% (n=46)	100% (n=602)
Breastfeeding, pregnant or trying to conceive	(n=393)	(n=2)	(n=3)	(n=2)	(n=8)	(n=408)
A specific medical issue meant it was no longer suitable	94% (n=564)	2% (n=13)	2% (n=10)	1% (n=7)	1% (n=8)	100% (n=602)
Switched to a treatment thought more effective	76% (n=459)	4% (n=25)	5% (n=29)	6% (n=34)	9% (n=55)	100% (n=602)
Wanted to manage MS without drugs	68% (n=408)	12% (n=73)	11% (n=64)	5% (n=29)	5% (n=28)	100% (n=602)
Wanted to manage MS without taking illegal drugs	47% (n=284)	11% (n=67)	13% (n=76)	11% (n=64)	18% (n=111)	100% (n=602)
The financial cost	50% (n=303)	12% (n=71)	15% (n=92)	12% (n=73)	11% (n=63)	100% (n=602)
Concerned about prosecution	49% (n=293)	13% (n=80)	12% (n=74)	11% (n=65)	15% (n=90)	100% (n=602)
No longer experiencing symptoms originally taking it for	85% (n=509)	6% (n=33)	5% (n=29)	2% (n=11)	3% (n=20)	100% (n=602)

The figure below shows that respondents reported using cannabis for a wide variety of symptoms.

The majority used cannabis to try to manage spasticity and pain. 63% (n=379) used it for muscle stiffness, spasticity and spasms. 54% (n=326) used it to try to manage their pain.

Figure 7: Symptoms respondents were using cannabis for

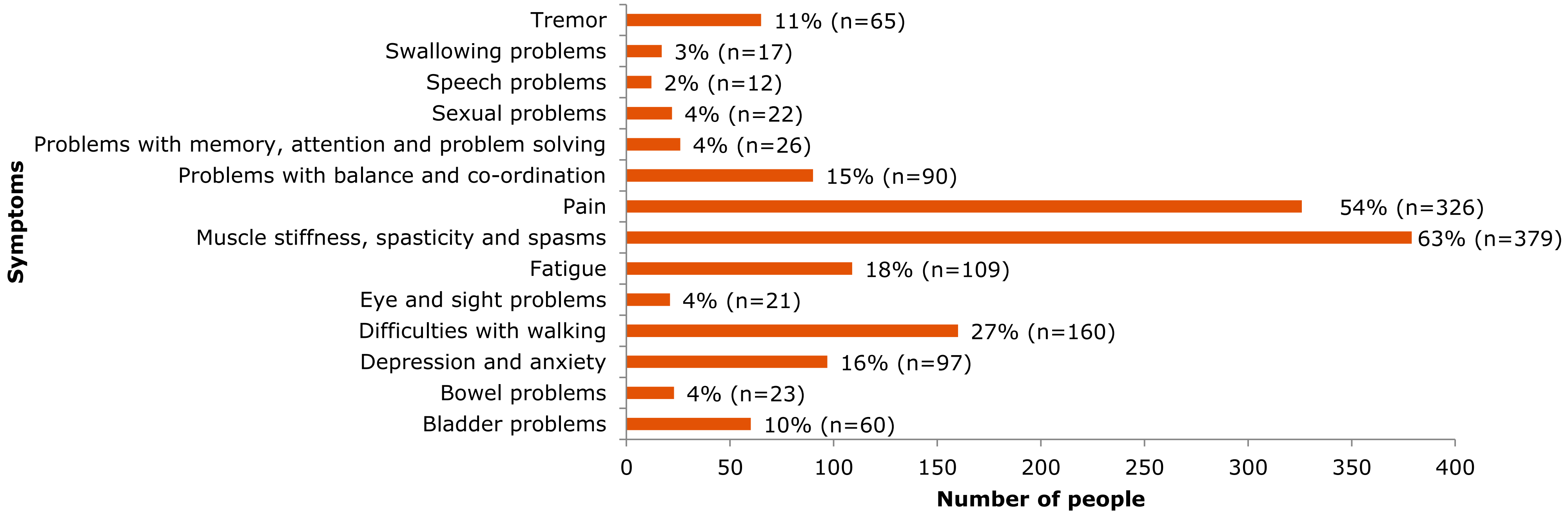
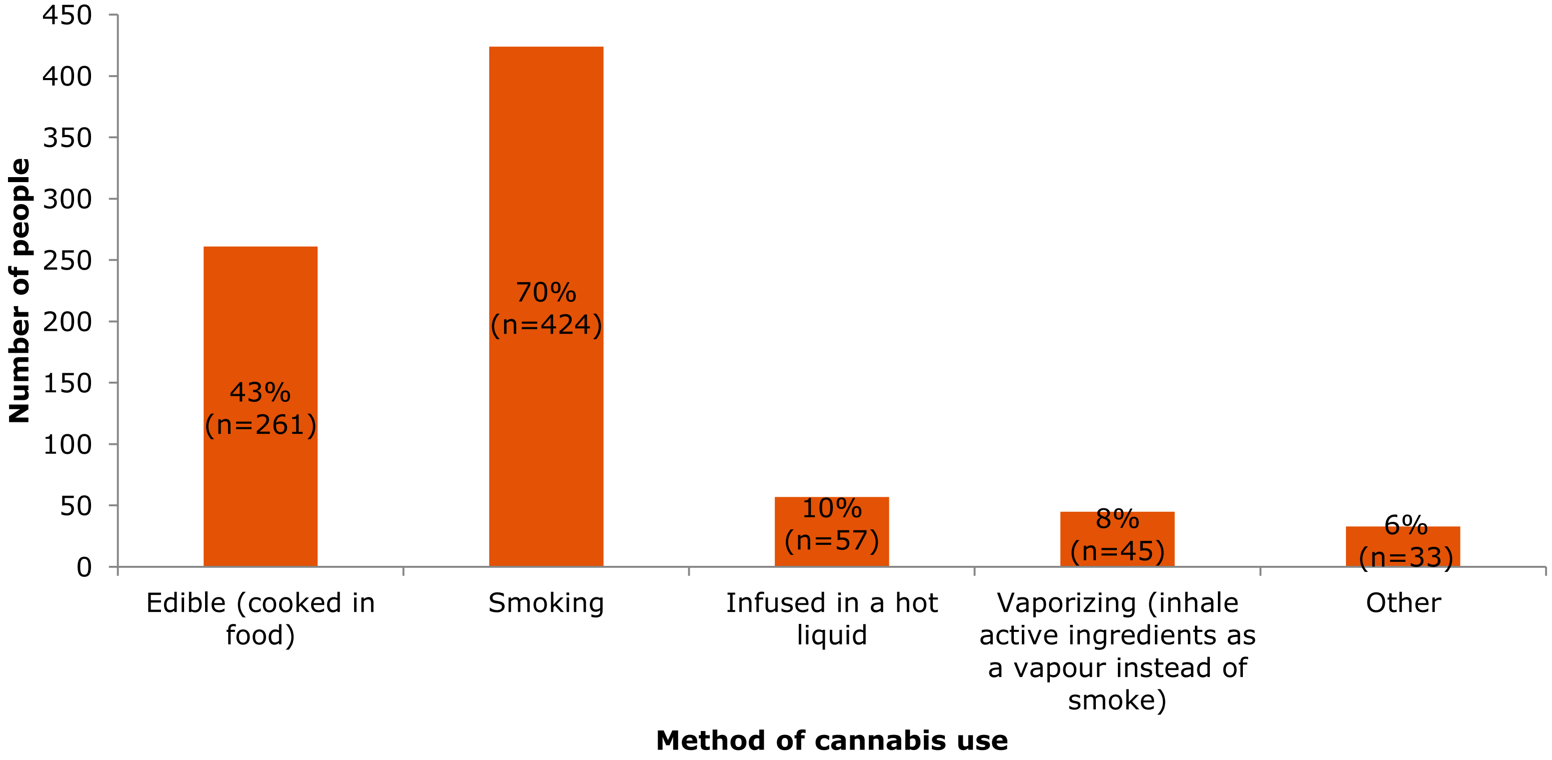


Figure 8 provides a breakdown of the ways people who have previously used cannabis have taken it. 70% (n-424) of people have smoked it and 43% (n=261) have taken it cooked in food.

Figure 8: The ways people who previously used cannabis have taken it



Those who had previously used cannabis to try to manage the symptoms of their MS were given the opportunity in the questionnaire to provide further details of the reasons why they were using cannabis, as well as why they stopped. Four main themes were generated from the data:

1. Costs and benefits
2. An illegal drug
3. Availability of other options
4. Questioning effectiveness

Costs and benefits

Understandably many people discussed either side effects that they had experienced as a result of using cannabis, or side effects that they were concerned about. Neil described that he ‘was having awful side effects including paranoia and irritability’ and Sidra stated that she ‘tried marijuana a few years ago but it seemed to affect [her] ability to walk from the garden back to the house. So [she] did not try it again’.

Others acknowledged that whilst using cannabis seemed to have a positive influence on some of their symptoms it exacerbated others. For example Emma explained that ‘It increased [her] dizziness, so although the pain was gone [she] was more physically unbalanced’ and Moira was concerned about the ‘possibility of addiction’. Natalie stated:

> ‘I stopped using cannabis because I was forgetting where I was or where I was driving. I was driving safely just not sure where I was.’

However a small number of people did not feel that they experienced any side effects of using cannabis or that they were able to manage them:

> ‘I use it when I feel need to and have never had any unpleasant side effects unlike the prescribed medicines I take regularly’.

> ‘I smoked marijuana a few years back, possibly for pain but after a seizure that medics say was linked to the fact that I had smoked marijuana previously. I don’t agree that this would have caused me to have had a seizure but suppose I had to take notice!...One thing that I know for sure happens to me when I have smoked is that my blood pressure drops. So I am always careful that I don’t let this happen (I make sure that I have something sweet on hand)’

An illegal drug

A large number of people wrote about access being a contributing factor to them stopping using cannabis to try to manage their MS symptoms. Respondents’ comments included ‘lost my trusted source’ and ‘I could no longer find it in my local area’. Amelia explained how the death of her “supplier”, which was not related to cannabis use, meant that it was no longer something she could ‘get hold of discreetly anymore’. Craig stated that ‘it happened once and the neighbours who were smoking it have now moved away so I have no access to it’.

Others explained how they had tried cannabis whilst abroad and coming back to the UK meant that they stopped using it. For example Diedre wrote ‘I came back from

Amsterdam and it is not legally available here – otherwise I would have got some more' and Christine explained

> 'I do not know where to buy high quality cannabis. I smoked it in Amsterdam after discussing the strains with reputable coffee houses and selecting one with high medicinal content'.

The illegal nature of cannabis means its 'quality' is highly variable, making it 'Increasingly hard to source hashish or varieties other than unbalanced skunk with unpleasant highs' for Mark. This played a role in his decision to stop using cannabis.

Ultimately for some people the reason they stopped using cannabis was that they did not want to 'break the law'. Marie described:

> 'I only used cannabis once – it did have a positive influence on my symptoms but I did not want to get into using illegal drugs so decided to stick with prescribed medication despite the fact that they were not having the same positive effect that cannabis had!'

For some people the 'Bottom line is cost and being prosecuted'. For this group of people the fact that cannabis is illegal is the main reason they are no longer using it.

Availability of other options

Some people reported that they had stopped using cannabis because another legal option became available to them. In most cases this was Sativex. Comments included 'Got Sativex on the NHS' and 'I changed to Sativex once it became available'. Others explained how they 'think taking Sativex may help' or that they 'would definitely consider Sativex in the future (if it was available)'.

Constance described how 'More effective, legal options became available. However [her] legal meds are becoming less effective as time goes by'. Cassandra 'found a blend of valerian, hops, yarrow tea had the same useful relief of MS symptoms without the cannabis side effects'.

Questions about effectiveness

For some respondents the questions they had about the effectiveness of cannabis use based on other people's experiences led them to try it. Sharon 'had just heard that sometimes cannabis helps people with MS' and Tracy explained 'A friend of a friend with MS suggested I try it as she feels it has helped her hugely and I wanted help quickly'. Harry was 'in Amsterdam on a short break and wanted to see its effects' and Kay 'Just tried to see if it helped anything'.

In some cases individuals tried using cannabis because they 'basically would try anything as there is nothing else'.

Kay was not alone in finding no beneficial impact on the symptoms of her MS. Many respondents did not find that cannabis helped with their symptom management, which is why they no longer use it. Andrea reported taking part in a clinical trial for cannabis and found that 'it was of no benefit to [her] MS'. She also explained that the report from the clinical trial confirmed this. Many respondents explained that they 'Only tried it a few times to see if made a difference. It didn't have that great an impact'.

A small number of people who had previously used cannabis found that it did help with the symptoms of their MS. However they had not continued using it as they were waiting until they have no other options available to them.

Another factor that resulted in people stopping using cannabis was the method in which they took it. Many people explained that they were not using cannabis because they ‘did not want to smoke’.

Summarising the decision to stop using cannabis

- 18% of respondents reported that they were no longer using cannabis as they wanted to manage their MS without taking illegal drugs and 15% were concerned about prosecution.
- The illegal nature of cannabis meant that sourcing the drug was a major reason many people stopped using it.
- Other symptom management options becoming available led some to stop using cannabis.
- Other respondents felt that cannabis was not helping their symptoms or that the side effects were too severe.

Group 5 - Currently using cannabis

This section focuses on the 7% (n=260) of respondents who were using cannabis to try to manage the symptoms of their MS at the time of filling out the questionnaire.

The main reason people gave for using cannabis was the belief that the benefits outweigh the side effects. 56% (n=145) said this was completely the case. 47% (n=121) reported using cannabis because they believe that it is a natural remedy and 42% (n=109) believe it is more effective than licensed treatments. 40% (n=103) completely agreed that they were using cannabis because they could not access licensed treatments.

Table 3: Reasons respondents are currently using cannabis

Reasons currently using cannabis	**Not at all**	**To a small extent**	**Somewhat**	**To a large extent**	**Completely**	**Total answered**
Could not access licensed treatments	18% (n=47)	10% (n=27)	18% (n=47)	14% (n=36)	40% (n=103)	100% (n=260)
Believe it is a natural remedy	6% (n=16)	8% (n=21)	16% (n=42)	23% (n=60)	47% (n=121)	100% (n=260)
Believe it is more effective than licensed treatments	10% (n=25)	7% (n=17)	21% (n=54)	21% (n=55)	42% (n=109)	100% (n=260)
Licensed symptom management treatments have not helped	21% (n=54)	15% (n=38)	25% (n=66)	20% (n=52)	19% (n=50)	100% (n=260)
Less expensive than other symptom management options	43% (n=112)	9% (n=24)	18% (n=47)	14% (n=36)	16% (n=41)	100% (n=260)
The benefits outweigh the side effects	3% (n=8)	5% (n=12)	13% (n=34)	24% (n=61)	56% (n=145)	100% (n=260)

The figure below indicates that respondents used cannabis to try to manage a variety of symptoms.

68% (n=176) were currently using cannabis to try to manage pain, and 62% (n=161) were using it for muscle stiffness, spasticity and spasms.

Figure 9: Symptoms respondents are currently using cannabis for

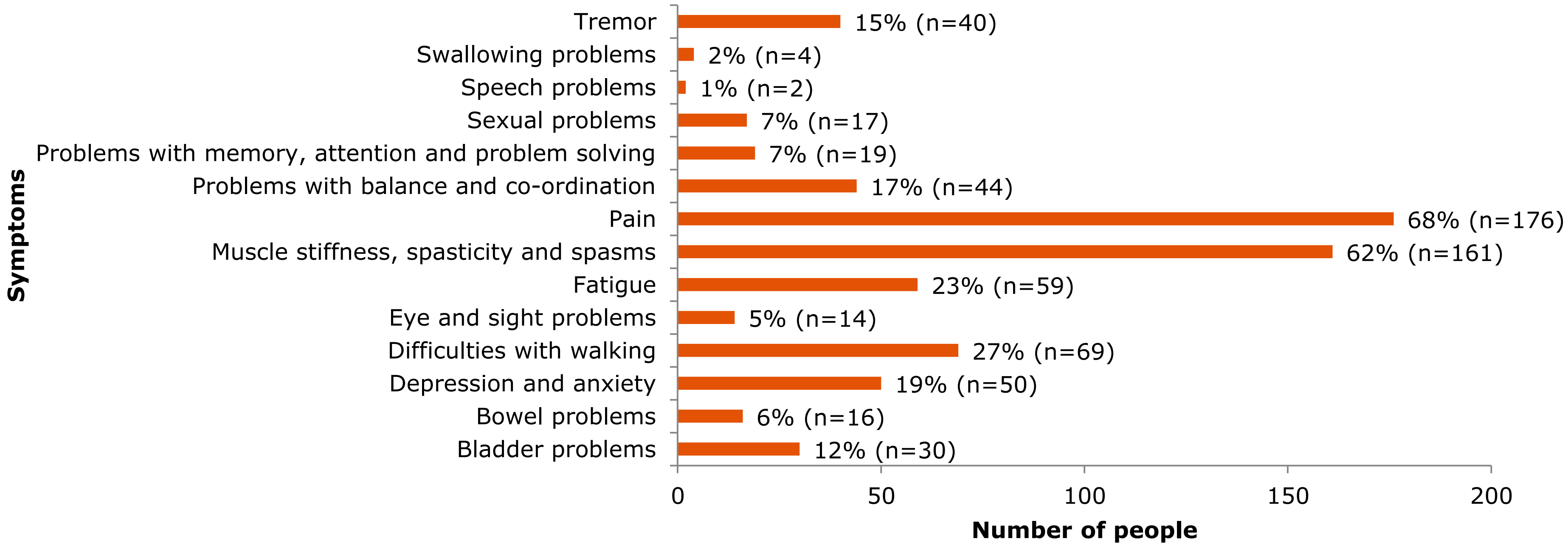
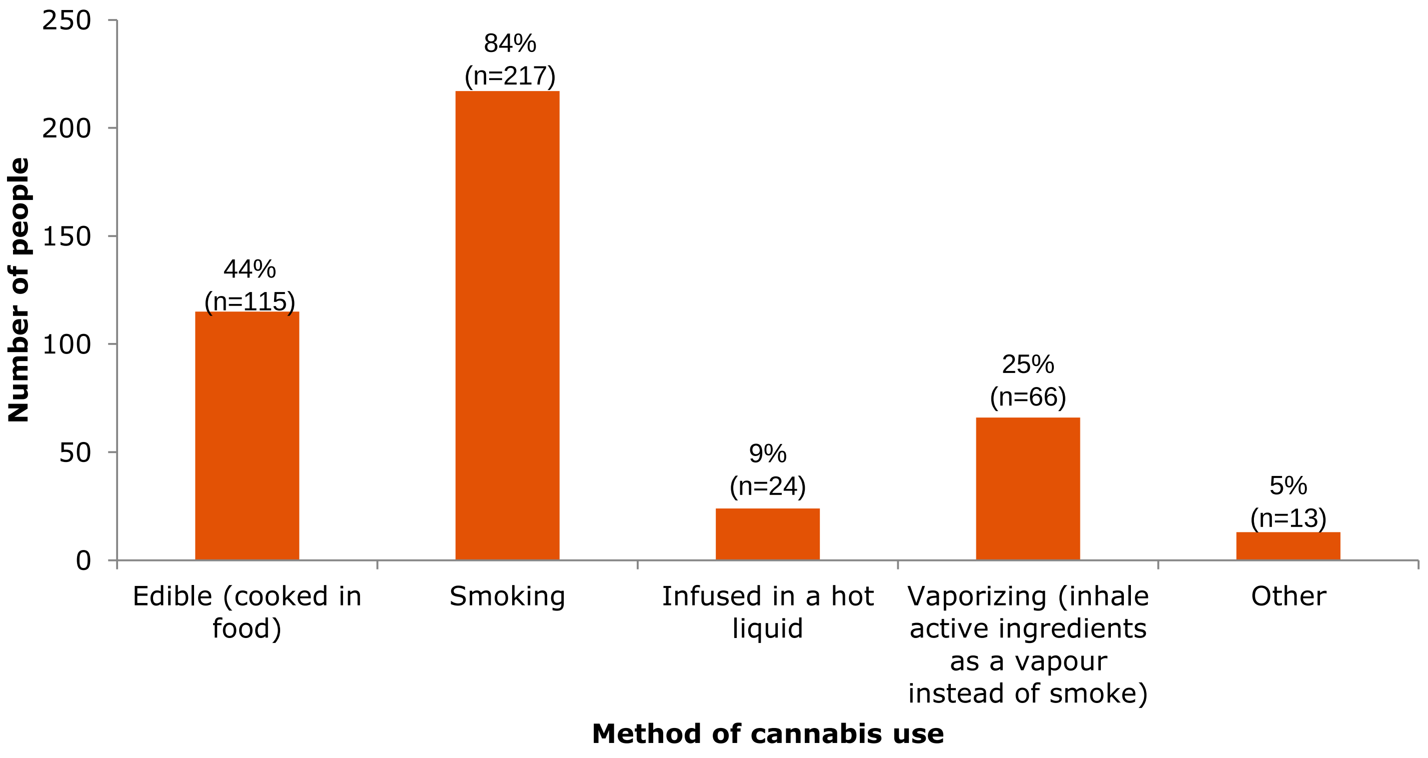


Figure 10 shows that 84% (n=217) of people currently using cannabis have smoked it and 44% (n=115) have eaten it in food.

Figure 10: The ways people who are currently using cannabis have taken it



All of the respondents who indicated that they were currently using cannabis to try to manage the symptoms of their MS, were given the opportunity to provide details about both the symptoms they were using it for as well as any other reasons that led them to using it. Three themes were generated from this data relating to cannabis:

1. A form of symptom management
2. The only option
3. Curiosity

A form of symptom management

The quantitative data presented earlier on page 25 showed that people were mainly using cannabis to try to manage their pain, or muscle stiffness, spasticity and spasms. Many people wrote about how they use cannabis for 'pain relief' in further depth. In some cases individuals wrote about how a reduction in pain can have a significant impact on other aspects of their life. For example Kate explained:

> 'It's helping my hip and back pain and relaxes my leg muscles, so I am able to do exercises with no pain and can do them easily.'

The impact that cannabis use can have on sleep was emphasised by many and in some cases this was linked to a reduction in the pain that they were experiencing. Zoe stated:

> 'I also find that when I use cannabis I take less pain medication. I only have to use a minimal amount twice a week to alleviate symptoms. I also sleep well as the pain is greatly reduced when I have had cannabis which helps my fatigue too.'

People described how insomnia can 'impact heavily on other symptoms' and that they find that cannabis can have a positive effect on this. This could help to explain the wide variety of symptoms that people reported using cannabis for.

It is worth acknowledging that a small minority of people currently using cannabis did discuss some of their negative experiences of the drug relating to symptoms. Andrew reported that 'it exacerbates balance/coordination which can be dangerous some times' and 'while cannabis seems to be useful for people with spasms [John has] never found it has any impact on those'. However, John then continued:

> 'Main usage comes largely from a need for sleep - if any of my symptoms are severe enough to cause chronic sleep deprivation and I'm raising between 1am and 3am, then after a week or so of that then I'll use cannabis, either when I go to bed to hopefully get a longer sleep OR have one rolled ready for when I wake at silly o'clock to get me back to sleep and to try and kick start a better sleep routine so that waking so early doesn't become a habit.'

For some the decision to use cannabis as a form of symptom management developed from a belief that they would experience fewer side effects than from legal symptom management treatments. For example:

> 'There are no side effects to smoking cannabis. Obviously to your lungs of course, but it's nothing like say waking up with a hangover.'

> 'Never experienced 'side effects' from marijuana...I don't get high or zone out, it simply helps to alleviate some of my symptoms'.

Others felt that cannabis is more 'natural' than legal symptom management treatments meaning it is somehow more appropriate to use. Some held very strong views about this:

> 'I want to stop all medical treatment and stick to 'natural' cannabis.'

> 'I believe that this plant was put on the planet for MS.'

In addition some people found using cannabis was more convenient than legal medication. Jessica described the benefits of being able to 'have access to medication ... without having to wait three weeks to see a GP, get a prescription, read the information and comply with that etc.' She also wanted to emphasise that she does not like 'to criminalise others in order to benefit from cannabis use'. Through growing plants at home Jessica has access to her own supply without having to use drug dealers.

So, many of those currently using cannabis reported that 'it eases symptoms quickly, effectively and in a controllable way.'

The only option

Some people believed that cannabis was the only available option for them and explained that they had simply not been able to access any of the licensed symptom management treatments:

> 'I haven't been offered ANY type of MS medication. I have been told there's no more that can be done for me'.

> 'I can't get a licensed symptom management treatment. Marijuana is unpredictable and carcinogenic, I'd rather not feel the need to use it but there's no other option available to me'

For some, negative experiences of healthcare professionals have led to cannabis use. Marie described how she is 'trying to manage [her] own MS, [after having] bad experiences with narrow minded, blinkered, unsympathetic neurologists and doctors'

Many people wrote specifically about Sativex. Daniel explained that he uses cannabis because he has 'been refused Sativex' and Ellie feels that she has been put in an uncomfortable position:

> 'I am using cannabis because I am unable to obtain Sativex. I would rather use Sativex than be in the position of using a drug dealer'.

So some individuals are using cannabis because they cannot access legal medication. Kully finds the process that she would have to go through to try Sativex unacceptable:

> 'I'm treating myself because I refuse to go down the list of drugs that they need me to go through before I would get Sativex. I'm not willing to put these drugs in my body when I've already found something that works and has no side effects'.

The financial implications of taking Sativex played a large part in some decisions to use cannabis. Neil started using cannabis 'as an alternative to Sativex as Sativex is so expensive' he paid £460 per script and stated he does not 'have a bottomless pit of money'. Susie has 'been waiting for Sativex spray for years. [Her] doctor wants [her] to have it but the health authority will not fund it'.

Others have heard of similar difficulties associated with accessing Sativex and listed this as a reason for using cannabis:

> 'I was aware Sativex is very expensive, therefore unlikely to be prescribed, unless you are on your last legs. By using medical (same strain which is available in some pharmacies abroad) cannabis, I am getting the same chemicals in Sativex.'

However, a few people had been given the opportunity to try licensed treatments but found them 'unsuccessful and unsuitable':

> 'Cannabis is the only thing that helps me so I will use it, just unfortunate all the money given by the government goes in a drug dealers pocket (£20 for 1.4g).'

He continued by explaining that he feels that he has been 'trapped in a horrible 'skint' cycle by the government'. Sandra cited using cannabis because it 'is a lot cheaper than the meds and more pure and less side effects.'

The side effects of licensed drugs were in some cases factored into the decision to use cannabis. If Sophie 'had continued with the licensed drugs for treatment of pain and spasms [she] would be a zombie, unable to work and would lose [her] home.' So she stopped taking licensed pain medication and began using cannabis.

Whilst some people reported that they would use cannabis over the licensed treatment options, this was not the case for a large proportion of those using cannabis:

> 'I wish that I didn't have to break the law in order to feel more normal but this is definitely better than how life was! I have not been offered the chance to have a legal substitute; I would more than welcome the chance NOT to have to use illegal drugs'.

For many cannabis seems to be the only option, as accessing legal treatment options is proving impossible or they do not appear to be effective. As well as these issues, for some, cannabis appears to be the only option to help them cope with the symptoms of their MS. Statements such as 'I feel it just gives me a lift so that I can cope with it', 'It's the only thing that helps' and 'It makes me realise that things are not so bad' demonstrate the importance of cannabis in their lives. People wrote about cannabis helping with stress, anxiety, depression and increasing wellbeing. Darren described using it 'as a last resort' for when other techniques such as visualisation and NLP are not working.

Lisa describes the importance of cannabis to her:

> 'It makes it easier to get through the day. I have suffered with depression and anxiety since 2010 and really didn't want to have to go down this route as I have read what cannabis use can do to you. After being unable to find adequate pain relief and having started to self harm, my friend (who also has MS) convinced me to try cannabis...Since taking cannabis I've found that life is now manageable. I've not self harmed in the last 12 months and am looking to come off the anti-depressants in the next few months.'

Curiosity

Whilst many people feel that using cannabis is their only option, others reported using it out of a sense of curiosity. Craig uses cannabis because he has 'heard it helps - helps with what [he is] not sure' and others are currently using it because people around them have told them about their experiences.

Some people are not sure about whether it is actually making a difference but 'without being able to "wind the clock back", with MS, it is impossible to say... But who knows?' Others have used cannabis before diagnosis and 'wondered if that covered up the symptoms of MS'.

Georgina reported that her 'GP, nurse and neurologist are very like-minded regards the benefits' of cannabis for MS'

Summarising the decision to use cannabis

- The main reasons people reported using cannabis was about beliefs. These included the belief that the benefits outweigh the side effects, that cannabis is a natural remedy and that it is more effective than licensed treatments.

- 40% reported that they were completely using cannabis because they could not access licensed treatments. The qualitative data reflected this with the theme 'the only option'. Here many people explained their difficulties in trying to access licensed symptom management treatments.

- The main symptoms people stated they were using cannabis to try to manage were pain, and muscle stiffness, spasticity and spasms. However people reported using cannabis for a wide variety of symptoms. This was emphasised in the comments people made, especially regarding the positive impact cannabis use can have on sleep and the influence this can have on other symptoms of MS.

- A small number of respondents felt that they were using cannabis out of curiosity or enjoyment.

- The majority of people currently using cannabis have smoked it or eaten it in food.

Thematic analysis of symptom management strategies

'Anything else you would like to tell us about in relation to the ways you are managing the symptoms of your MS'

The following section presents the main findings that have been generated from the thematic analysis of this data from the final question (see above). The main findings have been organised into six main themes:

1. Managing symptoms
2. It's my MS
3. Impact and support of others
4. 'But it's a bloody hard struggle'
5. A lottery of treatment and care
6. Experiences of healthcare professionals

Each of these main themes will be discussed in the following sections and will be supported by direct quotes taken from the questionnaire responses.

Managing symptoms

A large amount of the data related to ways of managing the symptoms of MS. The following subthemes were generated:

1. Treatments
2. Coping Strategies

There were a vast number of symptom management strategies mentioned in the survey. A large amount of respondents used evidence based treatments to fully or partially manage their symptoms. However many also reported using non evidence based treatments in some way. The MS society advocates evidence based symptom management treatments. They also provide information online to help people understand the risks and benefits associated with alternative treatments, and make an informed decision[5].

Treatments

Many people wrote about treatments that they had tried, as well as their effectiveness. It became overwhelmingly clear that people with MS not only experience many different symptoms but that they try to manage them in a wide variety of different ways.

> 'How one person manages their symptoms is unique to them. There is not a one size fits all method of management'.

Many respondents wrote about the importance of diet and exercise, and the impact that this has on their MS. People felt that running, swimming and cycling helps them to remain mobile and improve their strength. For some the benefits of physical

---

[5] The MS society provides information and advice on symptom management treatments at https://www.mssociety.org.uk/what-is-ms/treatments-and-therapies

activity were both psychological as well as physical. For example Jim said that 'exercise is very important for me to maintain strength and enjoyment of life' and Amy stated 'I do go to the gym 3 times a week which helps me mentally as well as physically'.

Large numbers of people felt that what they eat influences the symptoms of their MS. As a result, individuals wrote about the importance of eating a healthy balanced diet. Others described how they had altered their diet to be vegan, gluten free, low in saturated fat, without red meat or a high plant based diet. Many explained that they follow the George Jelinek Overcoming MS diet[6].

A small number of people wrote about the impact that drink has on their MS. Some 'find alcohol in moderation helps' whereas others avoid consuming alcohol all together as it has a negative effect on their symptoms. Experiences of caffeine also vary substantially, with some people completely avoiding it and others drinking 'lots of real coffee', due to the impact it has on symptoms.

People reported using many different medicines for the symptoms of their MS, and found their effectiveness variable. These included disease modifying therapies, Prengabalin, Amitriptline, Tramedol, Baclofen, Botox, Gabapentin and painkillers.

For many talking therapies played an integral part of their symptom management regime. Individuals wrote specifically about the benefits of cognitive behavioural therapy and mindfulness techniques.

> 'All about self-management with a bit of help from medics. Talking therapy is useful'.
>
> 'I took part in an 8 week Mindfulness course as part of a study into its effectiveness. Very useful; mind over matter, being kind and non-judgemental of yourself'

It is almost impossible to list all of the ways that people reported trying to manage their MS. These included meditation, Pilates, yoga, tai chi, massage, reflexology, neuro-linguistic programming, stretching, reiki, aromatherapy, functional electrical stimulation, evening primrose oil, starflower tabs, Chinese medicine, speech therapy, acupuncture, snake venom, low-dose naltrexone, omega 3, chronic cerebrospinal venous insufficiency, vitamins and hyperbaric oxygen therapy. Some respondents reported travelling abroad to try treatments that are not available in the UK. For example Jake was 'having stem cell therapy in Zurich' and Grace had 'CCSVI treatment done in Frankfurt'.

It was important to some people that managing their MS did not involve taking any drugs.

> 'I have never taken medication. I have always managed my MS by acupuncture and a lot of prayers and faith in God.
>
> 'Self-help only, no drugs'

---

[6] Some people feel that following a special diet improves their MS symptoms. However at the moment, there isn't any conclusive evidence to suggest restrictive diets are effective. You can see our information on MS and special diets at https://www.mssociety.org.uk/what-is-ms/treatments-and-therapies/diet/special-diets-and-ms

The number of treatments and therapies people have tried to manage the symptoms of their MS is overwhelming and it seems their effectiveness is different for each individual, in some cases effectiveness of treatment is not the only consideration and other factors were taken into account.

‘It’s a delicate balance between managing the symptoms and the side-effects of medication. It comes down to what I can personally deal with, e.g. I’d rather be in pain than fatigued’.

Coping strategies

People seem to be using a range of different coping strategies to manage their MS. These include interacting with others, positivity, ignoring the symptoms of MS, positioning the symptoms as something that can be ‘fought’ and the importance of ‘listening’ to the body.

For some feeling part of an MS community was important when managing the symptoms of their MS. The ability to meet other people with MS was helpful to people like Jane, who stated ‘I meet with other people with MS regularly which I think really helps’ and for Amy hearing about ‘others personal experiences’ was useful. However, as with all aspects of MS, this was not the case for everyone. For example, Becky ‘found it too depressing and stressful being around other people with MS’. It is important to note that in some cases people emphasised the importance of social interaction generally. Meeting others, spending time with friends and trying new hobbies were seen as highly important and in some cases these linked to some of the following strategies discussed below.

> ‘I meet a small group of others with MS with whom I feel I can share time with, which gives me emotional strength’.

Many people wrote about the importance of having a ‘positive mental attitude!’ and for some a sense of humour was vital when managing the symptoms of their MS. Dan explained that he tries ‘to keep a positive outlook on life and a wicked sense of humour and try to find something to laugh about in the black moments’. Emily wrote about managing her symptoms ‘With humour and optimism! If that starts to fail I resort to antidepressants’ and Anita responded ‘Laughter for me. Peter Kay. You have to and my cat helps’.

Another strategy that some respondents seemed to employ involved ignoring the symptoms of their MS. Comments included ‘ignore it and get on with life’ and ‘still try to lead a “normal” life. Meeting friends, meals out and visits to the pub!’ Nick stated: ‘I just try to get on with my life as normal as possible and ignore them symptoms unless they really are telling me to take a break.’

Many people used terminology associated with a discourse of war to describe their symptom management, positioning the symptoms as something to fight against. For example Arthur stated that ‘physiotherapy is always the main weapon against the symptoms. When a new symptom appears, I just need to find the right physiotherapy to fight it’ and Emma explained that ‘walk, walk, walk is [her] form of fighting’. Leo described how fundraising for the MS Society has meant that he has ‘met some wonderful people suffering with MS, we are all in this fight together, and together we will win this battle.’

Being aware of their body and its unique fluctuations was seen as crucial for symptom management. ‘Learn to pace and listen to your body’ was a key message that individuals conveyed. Neil wrote: ‘Listen to your body, rest when necessary and live life as normal and don’t think you are MS’. Some people placed a great importance on not allowing MS to become who you are and that maintaining a life away from MS is an essential strategy.

Rest and sleep were also seen as an essential way of managing MS symptoms. When some people felt that they were not getting enough rest they noticed a difference in their MS. John explained that 'plenty of rest and relaxation is essential for [him] when symptoms flare up' and Georgie stated 'fatigue is a big problem, so pacing myself is very important. Not always successful'. This concept of pacing was raised by many respondents, with people describing the importance of having a short sleep in the afternoon, as well as having a good night's sleep.

It seems extremely apparent that when talking about symptom management what works for one person may not for another. Each individual not only has different symptoms but also has different opinions and experiences of treatments, and may develop a range of different coping strategies. This complex interplay of factors means that managing the symptoms of MS is highly individualised and can result in multiple treatments and self-management strategies.

> 'Low saturated fat diet, supplementary high dose vitamin D, avoiding stress, CBT, good relationships with neurologist, GP, family and friends have all helped me feel in control of my symptoms'.
>
> 'A healthy mental approach to MS is vital. CBT, focusing on the positive outlook and counselling have all made a massive difference. Also personally monitoring and evaluating my abilities. Technology – e.g. using smartphone to aid organising. Reminders, notes, calendars, satnav, photographing things you need to remember. Photographing positive experience and memories. Drive an automatic car! Adapt your environment. Manage your day. Consider your diet. Drink plenty of fluids. Go de-caffeinated. As long as you are still breathing – you have more things right with you than wrong…work at smiling and being happy – the more you practice, the better you get. When you shit yourself – you might as well laugh – it's better than crying.'

Most people have tried many different ways of managing their symptoms, with varying degrees of success. 'It takes years to learn how to live with this condition. It is so variable'. Many respondents felt that symptom management involves 'basically experimenting and a bit of trial and error' and are unsure about whether treatments are helping them.

It's my MS

It was highly important to many individuals that people understand that it is their condition, only they are aware of what it is like to live with MS and ultimately they should be able to make the decisions about how they manage it.

Some people wrote about people around them making assumptions about what it is like to live with MS. For example, Robyn described how she feels about healthcare professionals talking about her symptoms. She said 'I get so fed up of them telling me how my pain feels. How on earth can anyone without MS know how it feels?' Jessica also described how she does 'find specialists sometimes are dismissive of [her] lived experience of MS. They can also be quick to dismiss queries about MS and new symptoms'. These types of experiences have led some people to ensure that the treatments they try are 'always driven' by them, rather than an MS nurse, neurologist or GP. Faye explained that she would like to try Sativex but her GP and neurologist told her that it would be no good for her. She continued by stating 'I would like to be the judge of that. How do they know my body better than me? I think not.'

Others, primarily those with progressive forms of MS, discussed how they feel they need 'to accept responsibility for managing the condition'. Christopher explained he has to 'manage it on his own and put up with the symptoms because nobody seems to know'.

> 'I know my own body so I feel I'm the only one who can manage symptoms, aside from medication, I meditate and I prefer time alone if I'm having a particularly bad day. I think this is because family, friends and health professionals really don't understand which is irritating/frustrating.'

Some respondents discussed a lack of understanding about MS and the symptoms amongst friends, family and the general public. Gregg said that he finds 'people do not understand MS like they do cancer. MS is not such a high profile disease'. However Michael felt that 'Generally the majority of people have heard of MS, very few seem to grasp the implications of living with the symptoms so I tend to "shut up" and "put up" with it'. Amanda reported similar experiences and explained that few people who do not have MS 'realise the impact MS has on a person's life. Neither do they understand that the management of MS isn't just about medications and treatments. Lifestyle and work make a difference too'. Most people who wrote about a lack of awareness of specific symptoms discussed fatigue. It 'Can be very difficult explaining to others as the word fatigue sounds like an excuse' and John 'wish[ed] people would be a little more understanding of fatigue. Understand why [he has] to stop and sit still for periods'.

People reported invisible symptoms being particularly difficult to explain to other people. Zoe described that this has led to feeling like 'a hypochondriac' when she mentions any symptoms. She commented that 'nobody knows how you feel. As far as others are concerned I look well so I am well. There is nothing I can do.' Di explained that the symptoms that 'can be hidden to the outside observer' have led her to managing the symptoms herself as it is 'simpler' than trying to explain them to others. Kim described some of the main symptoms that 'are extremely difficult to manage let alone put across to others'. These included 'fatigue and how debilitating it is, "everyone" gets TIRED is the usual answer and why don't you just go to bed, loss of memory, cognitive issues, speech problems all explained away by others as "we all lose our memory as we get older", "we all get a bit confused sometimes". She continued to explain:

> 'Life and managing MS is the most exhausting thing EVERY day, a good day for you can still be marred by others, my MS…is attacking my very character with all the shit that goes with that. I've lost my QUICK wit, I'm still witty just not as quick with it, processing information, responding to questions, not being able to bear heat…all these symptoms are not visible to the naked eye, can't blame people for not understanding that. In their mind if I was in a wheelchair or using my stick I'd be disabled…to them I'm fine'.

The majority of respondents emphasised the importance of being in control of one's own symptom management.

> 'We need to be enabled to make our own lives work, in the way we need them to. It is easier to overcome a problem and remain a useful citizen if

> you are comfortable with the way it is managed…i.e. let us choose which things work for us. With MS there is no one solution, different things work for different people, and the key is getting what works best for yourself'.

Impact and support of others

Whilst many respondents described the importance of the people around them understanding that it is their condition, some wrote about the impact their MS has on the people around them.

> 'MS symptoms have a bearing on not only the person with the condition but with their family and friends'

The respondents' discussed how grateful they felt having friends and family around them that could support them and who they could rely on. The importance of having a 'Good family who usually understand' was emphasised by many. For some people, like Ashley, this support is vital for living their lives. Ashley explained 'My partner and I go through everything together and without him I would be totally lost. Nobody else can help'. This support can be emotional, practical or financial.

In some cases the support received from other people has resulted in the person with MS experiencing feelings of guilt. Naomi explained that her parents and sisters help with managing her MS but wrote 'I feel sorry to put them through this trouble. I have a lot of guilt for just having MS!!', and Ibrar described feeling 'really upset about losing [his] independence and being such a burden to family and friends'. This concern about the impact MS is having on family meant that some people expressed worry over their family's 'mental and emotional wellbeing'.

> 'The pain and fatigue I'm going through at the moment is affecting my children's lives, I need a quality of life so my girls can get a quality of life themselves!!!'

For the majority of people friends and family are essential for helping with the management of symptoms, offering both physical and emotional support, but this can have a large impact on those around them.

> 'It is very difficult to put in words. MS changes your life. My wife says she loves me but hates my MS some of the time…I am lucky to have a wife, family and friends that help me deal with day to day life'.

'But it's a bloody hard struggle'

Whilst some respondents were fairly positive about managing the symptoms of MS, some wrote in detail about the difficulties of living with MS day to day.

Many people believed that the term symptom management was inappropriate and felt that they were 'not managing them. Just living with them'. Julia stated 'to be blunt I'm not managing them. I'm in constant chronic pain suffering extreme fatigue and I'm a prisoner in my own home' and Angela said 'I'm not managing at all. I take my

Copaxone and feel awful. I mostly just cry'. Understandably for many people with MS this leaves them feeling 'totally lost'. Dean stated:

> 'I'm now paralysed from the neck down and have little speech and am bed bound most of the day – what's left to manage, except a miracle cure!'

Rose also explained how MS has completely changed her life:

> 'MS is horrible, I need to take each day slowly. My mobility is very poor. My right hand and that side of my body is very, very weak, I'm very dependent on others doing things for me. I cannot go to church, write, cook, walk about, do simple things for myself, play the piano, shop, bath the way I like to, style and dry my own hair, relax on the floor as I used to, need I go on?'

The psychological impact of living with MS was clearly evident across many of the statements received. For example Charlotte said 'Just managing/existing on a day to day basis. I have a lot of 'demons' in my head that tell me constantly that I am a disabled person and so am worthless. It's very difficult'

Others explained their frustration at constantly looking to access suitable medication. Sam explained 'I feel frustrated as everything I want/need I have to fight for' and Sally wrote 'I'm too tired to keep trying to find the correct medication for my symptoms', illustrating the constant struggle that some people with MS face. For others the medication that they take 'rules' their lives which they 'hate', and others feel they no longer have any available options:

> 'My condition is very hard to bear. I am in extreme pain all day every day. None of the treatments have helped me. I want to go to Dignitas but I would prefer to die in my own bed and my family aren't supportive of my choice so I am stuck'.

> 'Every day that I cannot help myself is another day I am self-harming'.

Many people are desperate for an effective treatment for their MS, such as Matthew who stated 'Like all other MS sufferers (and we do suffer) I am waiting for a cure'. A few people wrote about how they have had to accept the changes of living with MS. Ed wrote 'I think I accept this is my lot in life…and I hate it!!' and Ben explained 'No choice – keep working and keep 'fighting' as much as possible. Any help/drugs that may work would be a welcome gift'.

The fluctuating nature of MS means that each day is very different. This inability to predict how their MS will affect them on a daily basis is extremely unsettling for some. Jean wrote 'I struggle from day to day, never knowing how I, or my body, is going to feel from one day to the next'.

> 'But I still struggle, I can't walk, and I know everything is still getting worse. I do exercises and I stand every 15mins, I do everything in my power to keep moving…but it's a bloody hard struggle'

A lottery of treatment and care

My MS My Needs 2016[7] revealed that access to symptom management treatments was exceptionally low. It has been established in this report that accessing treatments and financial considerations played a role in whether people chose to use cannabis or not to try to manage the symptoms of their MS.

Many people wrote extensively about their experiences of struggling to access treatments, as well as employment and financial implications of having MS.

> 'I think the amount of postcode lottery is disgraceful and pts are poorly monitored on drugs the NHS seem to think are some kind of choice accessory. Many other chronic conditions get prescriptions for free, why should MS be any different?'

Accessing treatments

> 'There could be something that would help me but without access to medications to try them it's impossible to tell. It's frustrating and frightening'.

Large numbers of respondents wrote specifically about Sativex and Fampyra, in terms of a lack of availability based on location or the amount of money a person has. Nigel discussed with his GP about whether he would be able to stop codeine and low dose sleeping tablets 'if Sativex was available in Somerset and he agreed. The postcode lottery in the NHS is cruel!' Danielle stated 'If I move to Wales I can be prescribed Sativex. Are we not a United Kingdom?' and Lisa felt 'lucky to live in Wales so will get Sativex prescription soon'. Gregg described how he had been prescribed Fampyra before he moved and that he would now have to pay privately to continue receiving it. He wrote about the huge difference if makes to his walking and that he hopes to continue to take it 'as long as it is effective and providing [he] can fund it as [he is] unable to work and therefore money is very tight. [He] would struggle to walk without it so would be very relieved if it could be obtained on the NHS'.

Jared also emphasised the importance of taking Fampyra, but the difficulties of funding it himself. He stated 'It suits me. I walk better and it helps with fatigue. Really need to get this drug via NHS'. Sophie also felt that she has 'to struggle to find money to pay for a prescription' of Fampyra. The treatment was described as being 'vital' and there was concern about no longer being able to access it. In the case of Joati, who is currently employed full time, being unable to access Fampyra would mean that she would 'have to stop work. The drug needs to become NICE approved and supplied by NHS, it is not expensive! PLEASE HELP!!'

The quotes below represent the feelings of a large number of the respondents and support some of the findings from the report about Sativex[8].

> 'I have been told that Sativex is not available in my area, only people that have Parkinson's are prescribed this drug, if I wanted to try it for my MS I would have to pay for it privately which is something I cannot do'

---

[7] Redfern-Tofts, D., Wallace, L. and McDougal, A. (2016) My MS My Needs 2016: access to treatment and health care. Technical report

[8] Redfern-Tofts, D (2014) Managing MS, Managing Spasticity: People with MS' experiences of Sativex

> 'All the meds I have tried have had very harsh side effects and no quality of life. That which does work, i.e. Sativex, has been refused due to cost!!'

> 'My neurologist has said that he would consider a cannabis based drug but he has only one patient on Sativex and that is a person who can afford to pay for a private prescription. I am on ESA and could not afford private prescriptions'.

Many respondents wrote about Sativex and the importance of being able to access it. Lindsay explained that a pain clinic consultant had 'recommended' that she gets Sativex 'but he cannot prescribe it and the GP wouldn't try'.

After three years of trying a variety of treatments Andy, who has secondary progressive MS, was prescribed Sativex. He was taking it for six years and felt that he had a good quality of life. He has found that it reduces his pain greatly, as well as helping with bowel and bladder problems. In addition to this Andy reported that there were no 'horrid' side effects and that it reduced the amount of time he spent visiting doctors. His current doctor will not prescribe it and Andy stated 'My quality of life has been greatly reduced due to a lack of Sativex.' This has left him feeling 'very angry' towards his doctor. Furthermore since stopping Sativex, Andy began experiencing bladder and bowel problems again and has had a number of falls requiring help from paramedics. 'Taking Sativex away from me has basically ruined my life'.

Some people explained that the lack of availability of these treatments is particularly devastating due to a lack of alternatives. Penny, who has primary progressive MS, said 'I get no DMDs and most drugs available for symptoms have unbearable side-effects. The fact that Fampyra and Sativex may not be available to me is pretty upsetting, it's like someone switched off the light at the end of the tunnel'.

In some cases respondents reported that their neurologists and GPs were trying to access these treatments for them but that it was Primary Care Trusts that turned them down. Amy thinks 'it is shocking that Sativex and Fampyra are not available widely on the NHS.' She particularly worries about the future; what will be on offer when her symptoms worsen, she retires from work and has a lower income?

Mital stated 'I have no idea what I will do without it. I cannot even begin to understand what my pain will be like without it. I will go back to using illegal sources if it is taken away.' Karl warned that 'If choices are not given to the patient through the legal path, the patient who is in pain will try everything and will ultimately end up in illegal paths'.

As discussed previously many people felt that the care they receive depends on where they live in the UK. Bernie acknowledged that 'MS 'care' seems to be so much better in the North West' and Derek explained how moving house to another Health Authority changed the care that he received:

> 'My previous neurologist said that there was nothing he could offer me for my tremors. My new neurologist asked me why I wasn't on Gabapentin? I now take this every day and most days are tremor free. I do not know what else I could be on to improve my symptoms. Why aren't the same treatments available everywhere?'

Stacy explained that she experiences bed sores and has been unable to access an airflow mattress. She lives in an area in Surrey and said 'This seems to be the only area just outside London that is not able to provide airflow mattresses!...I understand that people with MS who are in bed for more than 12 hours a day are receiving them in the South East and South London'.

> ‘I no longer have access to an MS nurse (and consultant) as my local CCG cut routine support for all people with long term health conditions to save money’

> 'Reorganization by NHS trust has deprived me of my neurologist and moved the one treatment to which I have had a positive response to a hospital an hour away and from an outpatient treatment to in patient!!'

> 'My neurologist has denied me everything I have ever asked to try...I am permanently in a wheelchair now. I am very very angry.'

Employment and financial implications

Many respondents wrote about their work and employers, with some feeling that 'Employers should understand the condition more'. People’s experiences varied considerably. Howard is concerned that his 'employer is not fully aware of MS in young people' and thus finds 'it difficult to manage fatigue at work purely due to lack of understanding.' Deidre worked for local government and described how she had been placed on sick leave by her employer as a result of having a fall. She had been 'banned' form working and her employers are 'refusing to pay Medical Disability until she is 65'. This means she will not receive any income for 15 years. Nancy reported:

> 'being treated very badly by my employer, I feel I am being discriminated against. I work full time and it is a daily struggle, my employer and my immediate line manager does not understand disability or illness. There should be more awareness of MS'.

The idea that there should be an increased awareness of MS amongst employers was raised by many and some people reported not disclosing their condition at work. 'I have not disclosed my condition at work as I don't want it to adversely affect my career. Most people believe the difficulties I have are related to arthritis which seems a much more acceptable condition for most people'.

Furthermore some people described the psychological impact that not being able to work can have.

> 'I had to take early retirement because of my MS and it was truly horrible process making me feel just worthless'

> 'When I have taken time off work to rest I become depressed as all I then seem to focus on is what I can't do and not what I can do.'

Others have had a more positive working experience. Sally is working from home and found her employer to be 'extremely supportive' and Crystal is 'Still working full time but working from home most of the week. A flexible and understanding employer and family are better than drugs'. The flexibility seems to be integral for maintaining a career. People wrote about the benefits of flexi time, starting and finishing early enabling an afternoon rest, and the ability to work from home.

> 'One of the biggest worries which impacts on my symptom management is the uncertainty of the replacement of DLA by PIP. The variable nature of the illness means by managing my MS and its symptoms very successfully I am in great danger of losing the one thing that keeps me positive and feeling in control of my illness - my car'

> 'I can't understand why there are drugs out there that can really help people with MS but unless you can afford them you just have to suffer with the problems'

The nature of the questionnaire unsurprisingly meant that many people chose to write about cannabis when asked if there was anything further they would like to tell us about managing the symptoms of their MS. A large number of the responses argued that 'Cannabis should be legalised, especially for medical reasons', with many referring to cannabis as being a 'natural' and 'harmless plant'. Some explained how they found it especially difficult to understand why it was not made available to people with progressive MS. Amy wrote 'I find it hard to believe that cannabis cannot be given to sufferers of PPMS as there appears to be nothing else available'. Some respondents also felt that they should be entitled to make their own decision about whether or not to use cannabis. Lance and Sadie argued that:

> 'The legalisation of medical cannabis is essential for any patient over the age of 18. We are adults and with the correct information and guidance we should be allowed to make the correct informed decision for our bodies ourselves. Stop nannying us, please'

> 'Quite frankly in any society that aspires to be free and open an adult should be able to purchase and use whatever substance they wish as long as they do not force it upon others…To prohibit what is essentially medicine and criminalize those who benefit from it is simply immoral'.

Not being able to use cannabis legally has left some people feeling that they are 'being prejudiced against and that [their] quality of life counts for nothing'. Andrea feels that she is 'basically left to get on with it' herself and that 'nobody cares.' She stated 'I have become a criminal by using cannabis, even though without it I am in severe pain, can't sleep, drive or function, and that's providing I can get out of bed. PLEASE legalise cannabis for medical use and let me grow my own so that I know it's clean and safe'. Pat has relapsing remitting MS and regularly uses marijuana to help with pain and fatigue; she explained 'I do not like buying it from shady street dealers as I don't know where my money is ending up, it is also dangerous. Sometimes I have no choice but to. I do grow some at home but again this is illegal and makes me a criminal.' She continues to describe how she does not 'want to be a burden on the NHS'. Laura wrote 'Cannabis is the only drug available to me that makes life with MS bearable. I've been arrested for possession of cannabis!...I'm 52 and don't even speed. I was growing for my personal use because I didn't want to put money into the hands of criminals.' Many people with MS using cannabis wished they 'didn't have to break the law'.

Some people expressed gratitude, making statements like 'Thank you that you are trying to do something about cannabis' and 'I am so glad that MS Society is raising the issue of the need of so many to access cannabis on medical grounds – thank you'.

A small number of respondents compared the dangers of cannabis use to both alcohol and MS treatments, arguing that it is safer than some legal substances. For instance Harry stated ‘I manage my symptoms by breaking the law but it’s criminal to stop me treating myself with a drug that’s never killed a single person and yet I’m legally given Tysabri, a drug that has the potential to kill and severely disable people’

Others described their positive experiences of using cannabis for managing the symptoms of their MS. People wrote about how cannabis can help with relaxation, spasms, pain, MS hug, sleep and fatigue. Kara found that smoking cannabis gave her ‘the best night’s sleep in years’ and Jason described how it helps him ‘to have the best quality, unbroken sleep ever. If you can’t sleep everything is worse’. Callum stated ‘Marijuana remains one of the most helpful things in controlling my MS, despite the guilt of knowing I’m breaking the law, and the difficulty of obtaining good grade product’.

‘I have and am taking many medications for MS. However, not one has been as effective as cannabis’. Alf used cannabis for 15 years and felt like his symptoms were under control, then stopped taking it after it was upgraded to a category B drug. This was partially due to a fear of prosecution but mainly ‘out of a much greater fear of [his] daughter (a respectable mother of two) being prosecuted for purchasing cannabis for’ him. ‘I was harming nobody…I was able to function on a daily basis and live an independent life by doing everything for myself. I quite enjoyed life really’. Since stopping his cannabis use his symptoms have worsened and he has become more dependent on others. He wrote ‘I am without a doubt more of a strain on society as a whole’. Alf continues to use cannabis occasionally for three-four week periods, and after a few days of taking cannabis again finds his ‘physical and psychological symptoms to be alleviated’. He finds that he can do household tasks again and that his pain seems to improve ‘and life was enjoyable once more’. When he stopped he ‘found symptoms returning and life becoming nothing more than a painful chore’. Alf questioned ‘What harm am I as a 55 year old man with MS going to cause society by taking cannabis in the privacy of my own home to alleviate horrible symptoms and a meaningless life of drudgery that I wouldn’t wish upon my worst enemies?’

A small number of people wrote about their negative experiences of cannabis or the reasons why they would not use cannabis. Caitlin smoked cannabis once and explained that it caused her to feel ‘out of control’ which is why she ‘didn’t want to do it again.’ Colin ‘would never risk trying cannabis’ as he believes it would only give ‘a euphoric relief.’ Neither would he ‘be willing to experiment with untried ‘cures’’. Furthermore Francis wrote about the impact that cannabis could have on mental capacity and explained that she would only consider using it if it was prescribed.

There was some discussion around the evidence for using cannabis as a treatment for both MS and other conditions. For example Sam reported that she has ‘heard so many wonderful things about the positive changes cannabis has made to people’s lives with all sorts of conditions’ and asked ‘why are people suffering when there is evidence out there!!!!!’ Ashley believes ‘cannabis should be allowed to be taken for medical reasons without fear of prosecution!!!It’s proven to help with lots of medical problems not just MS’.

Whilst some individuals explained that they would use cannabis if they were no longer able to access Sativex, others emphasised that they have no desire to use cannabis. Jamie explained that he feels ‘extremely strongly that [he] must be allowed to continue taking this incredibly effective and safe medication, and that it should be readily available to other people with MS'.

> 'I would really like to live in a world that I do not have to resort to be classed as a "criminal" or "druggie" just so that I can feel some relief. The two years I was prescribed Sativex were the best two years I have had physically and mentally since being diagnosed. I do not want to break the law. I do not want to get "high". I just want to feel some relief from the pain. I want to play with my son and I want to feel as "normal" as possible'.

So it seems that people who can afford to pay for private treatment have many more options than those who use the NHS. Natalie 'paid privately to see a private professor of neurology and he was shocked at the treatment [she] was not receiving'. Many respondents wrote about therapies and treatments that they have to pay for that they believe should be available on the NHS. These included massage, physiotherapy, botox, acupuncture, Low Dose Naltrexone (LDN), oxygen therapy, FES and Pilates. Paying for some of these has led to serious problems for some respondents, such as Daisy who stated 'I can't afford this and am going in to debt now, which is adding to my depression.'

Experiences of healthcare professionals

It became overwhelmingly clear from the responses received that people have a wide variety of experiences when it comes to both accessing treatments and healthcare professionals. Some individuals described how helpful they have found their MS team, whereas others found it difficult to access the appropriate help or healthcare professionals were not supportive. This has led to a lot of people feeling lonely and a belief that they have to manage the symptoms of their MS on their own. So, a large number of people wrote about how necessary it was to become an expert in MS themselves.

A small number of people wrote about how happy they are with the overall care they have received from a team of healthcare professionals. For example Amy discussed the importance of receiving 'All round support from a consultant, MS nurse, doctor and family' and John stated 'I am very pleased with the care I receive from the MS team at my hospital'. It seems that those who received healthcare from an interdisciplinary team of people tended to be more satisfied with their level of care. Peter found 'Over the years GP's and consultants, speech therapists, occupational and physiotherapists have been a great help'.

Many respondents wrote specifically about their MS nurses and how helpful they have found them, using terms such as 'invaluable' and 'offers me the very best support' to describe them. The majority of praise was given to MS nurses. 'Right treatment, right time? How people with MS make decisions about disease modifying drugs[9]' indicated that MS nurses played the most useful role in decision making about DMTs. Carla explained that whilst her neurologist does offer some advice she only sees him once a year and because of this she relies on her 'MS nurse for informed advice regarding the management of symptoms' and has a 'better relationship' with her nurse.

---

[9] Redfern-Tofts, D. and Holloway, E. (2014) Right treatment, right time? How people with MS make decisions about disease modifying drugs.

It is important to note that although many people wrote about the positive experiences that they have had of MS nurses, this was not the case for everyone. Sandra found that ‘Continence nurses are helpful but it would be MUCH more useful if MS Nurses were fully trained in neuropathic bowel and bladder symptoms’ and Alan found the ‘Neurologist very helpful but had no contact with MS nurses’. Josie stated ‘My particular MS nurse is useless. The other nurses, who I speak to on the advice line, appear to be much more on the ball’. Nicole is ‘astounded by the lack of help from the NHS’ and ‘horrified’ that she was refused Sativex due to her nurse’s ‘prejudice against the treatment’. She stated ‘I need help, not archaic hurtful opinions’.

Some people explained that they were waiting to see an MS nurse after being referred to them but this was taking longer than expected. So it appears that access to MS nurses is important for many and that they are better placed to deal with some symptoms than they are with others.

A lot of respondents had negative experiences of GPs, making statements such as ‘Any help would be better than a GP’ and ‘My GP knows nothing about MS’. Curtis has not seen a neurologist since he was first diagnosed nine years ago. This is due to the fact that his doctor ‘doesn’t feel this would be of any benefit’. Crystal felt that ‘GPs need to listen more, they put a very big brick wall up, and they don’t understand what you’re going through at all.’ She explained that neurologists, MS nurses and GPs all ‘need to listen to patients more’ and that accessing the right help is becoming more difficult. She has to wait longer for appointments, for months and in some cases years. Stacy explained that her ‘neurologist is great with the pain but 12 months is a long time for appointments with them’ and Dan commented that ‘It takes too long to see someone and get answers’.

Other people felt that access was not the problem and that it was more to do with them not finding their appointments very useful. For example Grace has seen three different neurologists in the past 16 months however ‘none have been significantly helpful at all’ and have not offered any treatments. Stephen refuses to see his ‘utterly useless consultant’ as he is ‘rude, arrogant, pre judging’ and has not seen him in the last four years.

> ‘My neurologist is totally dismissive about symptoms I tell him about…He also refused to carry out an MRI when I requested one as it’s been 15 years since the last one and I wanted to know if my condition had worsened i.e. more scarring. They’ve also lost my original scans! I have zero faith in any of them and just get on with it on my own. I’ve had this condition for 20+ years and nobody really seems to care (in any shape or form!)’

Tracey is ‘Very disappointed in the lack of help’ she has received from social services. She applied for help in May this year having never asked for help before and has been ‘Thoroughly disillusioned by their response’.

Respondents also wrote about the difficulties of negotiating different medical departments and that sometimes this can lead to problems in receiving the appropriate support. Some people felt that a ‘Lack of awareness in the wider medical community is a recurring problem, with incorrect or bad advice being offered due to lack of understanding/education’. Stella explained that this meant that she has had her ‘prescribed medication withdrawn by hospital staff who had no knowledge of the condition, or of the effects of sudden withdrawal where titration is required or substitution of some meds for others which were completely ineffective.’ Emma wrote that she keeps ‘falling into a black hole when it comes to the NHS’. When her MS has flared up and she has needed additional support ‘nobody knows where [her] paperwork is’.

Some people explained how healthcare professionals do not seem to communicate effectively with one another, it is not clear where the responsibility ultimately lies and that this can lead to issues with accessing symptom management support. For example Nicola feels that ‘Anyone working in neurology is always quick to specify any symptoms you are experiencing are nothing to do with MS and should seek medical help from a different field of medicine. People working in other fields of medicine see you have MS and decide the symptoms you are experiencing are to do with your MS and nothing to do with them.’ This means that ‘no health professional wants to take any sort of responsibility for the person with MS’ and Nicola has found occupational therapists are the only professionals that help with learning to live with symptoms.

Rosa does not have access to an MS nurse ‘due to bureaucratic muddle.’ She has found that discussing symptoms with a GP or neurologist, who she sees once a year, is ‘impossible’. She has found that medical care and pharmacies are set up for individuals who are experiencing symptoms that are constant. Her symptoms ‘vary all the time’, meaning that she may only require a drug for a short period and then not at all for many months. ‘The “system” doesn’t deal with that sort of variability’.

People also wrote about their experiences of healthcare professionals around the time of being diagnosed with MS. Some people found that they struggled to actually receive a formal diagnosis of MS. For example Darren who was first diagnosed in 2007 had to travel abroad to receive the diagnosis. He explained that it took two hours to be diagnosed in the Philippines. Darren’s neurologist in the UK did not agree with the diagnosis until last year. ‘It has taken nearly 10 years to get diagnosis and treatment in the UK.’ Nora felt that after receiving her original diagnosis she was ‘not given any support by the neurologist’ and was ‘just told to come back in nine months’. Whilst her ‘GP is sympathetic’ she explained that they are not an expert, she had an appointment with her neurology nurse but has not heard from her since and applied for PIP six months ago and is still waiting for a response. All of these mean that she feels ‘I have just been left to get on with it as best I can. That is the extent of “managing” my symptoms’.

A large number of respondents expressed feelings of being left to manage their symptoms alone. Leo feels that he has been left ‘on the scrap heap and forgotten by the medical profession as though there are no options left’ and Melissa explained that ‘To a large extent you are on your own.’ She continued to describe that having ‘Too many agencies lead to confusion. Too much information and too many agencies giving it – what we need is practical help and assistance.’ Melissa felt that the local MS Society branch is the ‘most useful in that respect.’ Sophia wrote ‘It’s difficult to get the information. It’s normally word of mouth through what other people say, haven’t seen my MS nurse for over 4 years’.

There were vast arrays of responses that echoed this feeling of having to ‘cope on your own’ and that ‘You just have to live with it and hope you make the right decisions.’ Many comments included phrases such as ‘I feel isolated’ and ‘Feel as I have been left to handle all of this on my own’. Cassie explained that:

> ‘When I have had help I feel as though it has been the option that is easy for them and that they guess at the problem rather than get to the bottom

> of it, hence a lot of getting things wrong and making the problem worse still.'

The feeling that people have been left to manage the symptoms on their own means that 'As a person with MS you need to become your own expert and need to fight for things to try and help with symptoms'.

Many respondents with progressive forms of MS wrote about how they feel abandoned by healthcare professionals. Jake felt that 'as soon as you have an alternative diagnosis on your records from RRMS it feels like no one wants to know anymore' and Jacobia wrote 'Just seems because I have PPMS nobody seems bothered. In October I saw my neurologist to be told there's nothing more they can do for me, see you in a year'.

Potential limitations

This research was primarily limited by the method of recruitment. Respondents followed the MS Society social media channels or were on the UK MS Register, meaning that they were likely to be a more informed and engaged group than the general population.

The fact that the questionnaire was online meant that only people with internet access could complete it.

Summary/conclusions

Each person with MS has different symptoms, opinions and experiences of treatments and develops different coping strategies. This means symptom management is highly individualised and can result in multiple treatments and self-management strategies.

Those who receive support from an interdisciplinary team of healthcare professionals seem to be more satisfied with their level of care, with MS nurses generally being seen as the most helpful health care professional. It was felt that the health care system as a whole was not set up to deal with fluctuating conditions and people experienced difficulties negotiating different medical departments. People have found it difficult to access the appropriate support leaving them feeling alone and needing to become an expert in MS themselves.

For many friends and family are essential for helping with the management of symptoms, offering both physical and emotional support, but understandably this can have a large impact on those around them. Invisible symptoms are particularly difficult to explain to people who have not experienced them, which can be extremely frustrating. Many people explained that only they know the realities of what it is like to live with MS and ultimately they should be able to make the decisions about how they manage their own condition. Living with MS can be ‘a bloody hard struggle’, with people feeling that they are forced to live with the symptoms rather than being able to manage them. Many people are frustrated at having to fight for the medication that has the potential to help them. Large numbers of people discussed the difficulties that they have had trying to access treatments and that access is affected by where someone lives and the amount of money they have.

22% of people surveyed had used cannabis to try to manage the symptoms of their MS at some point.

7% of people were using cannabis to try to manage the symptoms of their MS at the time of filling out the questionnaire. Two in five reported that they were using cannabis completely as a result of not be able to access licensed symptom management treatments and that it was 'the only option'. One of the main reasons people reported using cannabis related to their beliefs. This included the belief that the benefits of cannabis use outweigh the side effects, that it is a natural remedy and that it is more effective than licensed treatments. People stated that they were using cannabis to try to manage a wide variety of symptoms including pain, muscle stiffness, spasticity and spasms. Some described the positive impact cannabis has had on their sleep and the influence this has had on other symptoms of MS. A small number of respondents felt that they were using cannabis out of curiosity or enjoyment.

15% of respondents had used cannabis in the past to try to manage the symptoms of their MS but were not using it at the time of filling out the questionnaire. There were many reasons for this, including experiencing severe side effects or feeling that it was not helping their symptoms. For some the fact that other symptom management options became available resulted in them ceasing to use cannabis. 18% of those who had previously used cannabis reported that they stopped as they wanted to manage their MS without taking illegal drugs and 15% were concerned about prosecution. The illegal nature of cannabis meant that sourcing the drug was a major reason many people stopped using it.

48% of respondents had never used cannabis to try to manage the symptoms of their MS but acknowledged that the thought had crossed their mind and there were many reasons for this. The negative side effects of cannabis use and previous negative experiences of the drug were deterrents for some. Whereas many of this group reported that they would likely try cannabis if it was not illegal and that the concern about prosecution prevented them from doing so. For others gaining access to cannabis was simply not possible and the fact that cannabis is not monitored or regulated like legal drugs meant that safety was a major concern.

Whilst 78% of people with MS have not used cannabis to try to manage their symptoms, regardless of the current evidence many have used it and feel that they should be able to make this decision ‘without a fear of prosecution’. 72% of all respondents felt that medicinal cannabis should be legalised. With one in five people feeling that the legalisation of medicinal cannabis was currently either high priority or essential for them.

Making decisions about treatment are inescapably difficult and complex, and this is complicated further when struggling to access a treatment. Many people are frustrated that they have to fight for the medication that has the potential to help them.

People should be able to get the right treatment at the right time.

We're the MS Society.
Our community is here for you
through the highs, lows and
everything in between.
We understand what life's like with MS.

Together, we are strong enough to stop MS.

mssociety.org.uk

Contact us

MS National Centre 020 8438 0700
info@mssociety.org.uk

MS Helpline Freephone 0808 800 8000 (weekdays 9am-9pm)
helpline@mssociety.org.uk

Online
mssociety.org.uk
facebook.com/MSSociety
twitter.com/mssocietyuk

MS Society Scotland
0131 335 4050
msscotland@mssociety.org.uk

MS Society Northern Ireland
028 9080 2802
nireception@mssociety.org.uk

MS Society Cymru
mscymru@mssociety.org.uk

Multiple Sclerosis Society
Registered charity nos. 1139257 / SC041990
Registered as a limited company by guarantee
in England and Wales 07451571.

Let's stop MS together