



Northern
Ireland



MS treatment in Northern Ireland: is access still a lottery?



Foreword

So much has changed in the last three years. More disease modifying therapies (DMTs) for relapsing forms of MS are available than ever before. Public policy and guidance about how to treat and manage MS have been substantially revised. And, crucially, we now know that starting treatment with a DMT close to diagnosis improves long term outcomes for people with MS.



We conducted the first ever My Ms My Needs survey just over three years ago. The resulting report documented shortcomings and disparities in the services for the estimated 4,500 people with MS in Northern Ireland.

Building on this unprecedented research, this year we undertook a second survey to better understand if people with MS are getting the treatment, care and support they need, and whether anything has changed.

I am pleased that access to DMTs among those who could benefit has increased in Northern Ireland from 68% in 2013 to 77% in 2016 (the UK average is 56%).

This is real progress. As more treatments become available, we need to maintain and continue to improve access to these vital treatments.

Worryingly, people with MS continue to face an unacceptable lottery of treatment, care and support. Our recent 'End the Wait' campaign highlighted how access to important MS services, such as regular appointments with consultant neurologists and MS nurses, is highly variable throughout Northern Ireland. This is particularly the case for those with progressive forms of MS. MS services are struggling, resulting in long waiting lists, reduced quality of service, and impacting people's quality of life.

As more treatments become available, ensuring equitable access to quality services must remain a priority. If we want Northern Ireland to be a place where people with MS are in control of their health and care, and live full, independent lives, we urge decision makers to study this report and act on its recommendations.

Patricia Gordon, Director, MS Society Northern Ireland

About MS

Over 100,000 people in the UK have MS. It's unpredictable, and different for everyone.

It's often painful, exhausting and can cause problems with how we walk, move, see, think and feel. But it doesn't have to be this way. We're driving research into more – and better – treatments. For everyone.

Together, we are strong enough to stop MS.

Strength in numbers

We conducted a survey of 11,024 people across the UK with MS between February and April 2016, making this the largest collection of patient-reported data from the UK MS community to date.

The initial survey was run in 2013. Together, the results of the My MS My Needs surveys provide an opportunity to understand in detail how people with MS feel about their treatment, care and support.

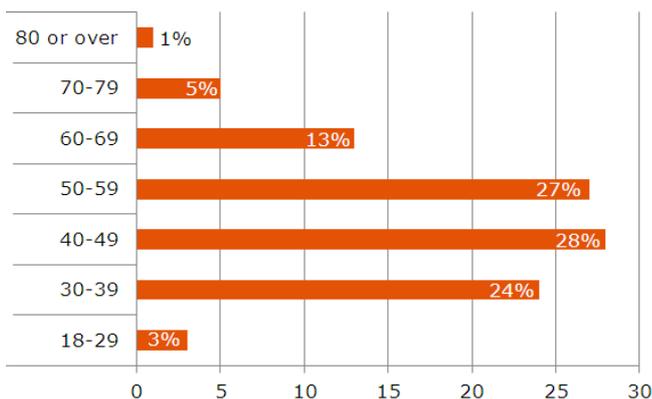
In 2016, 75% of respondents completed a paper-based survey, sent out to MS Society members, and 25% completed the survey through an email link, via the MS Register and Shift MS. Because of age and gender bias in our sample, the data has been weighted to be representative of the UK MS population.



3/4 of respondents were women

There are an estimated 4,500 people with MS in Northern Ireland.ⁱ This report focuses on the 366 respondents who live in Northern Ireland and their responses to the health and care aspects of the survey.

Figure 1: Age of respondents



Most respondents were aged 40 to 49 years, and 47% were diagnosed more than 10 years ago. 65% of respondents had relapsing remitting MS.

Many of the figures cited are the proportion of people with a given need who said that this need was met that is, the number of people who answered 'Yes' to a specific question, divided by the number of people who answered either 'Yes' or 'No, but I needed to'.

Key findings

- ▶ In Northern Ireland, 77% of those who could potentially benefit from taking a DMT are doing so (an increase from 68% in 2013).
- ▶ Only 5% of people are on a licensed treatment for the symptoms of MS (Sativex, Fampyra and Botox). This is up from 1% in 2013, but is still incredibly low.
- ▶ 80% of those taking a DMT had seen an MS nurse in the last 12 months, compared to 44% who are not taking a DMT.
- ▶ 89% of respondents had their need for access to a neurologist met (a decrease from 92% in 2013).
- ▶ 86% of respondents saw their MS nurse in a hospital setting with only 3% seeing their MS nurse in the community.
- ▶ 78% of respondents had not been offered a care plan by their health professionals.
- ▶ 15% of survey respondents answered “not at all” when asked if they felt that the professionals who help plan their care worked well together.
- ▶ 27% of respondents identified their GP as their key contact for health care and support in relation to their MS.
- ▶ 26% of respondents required support to remain physically active in the last 12 months but had not received any.
- ▶ One in four (26%) said they had not be able to access any emotional support and felt they needed to.

Treat Me Right

Our number one goal is to ensure people with MS have access to effective treatments. The MS Society believes that every person with MS should have access to the right treatment at the right time, no matter where they live.

Access to disease modifying therapies

In recent years, several new disease modifying therapies (DMTs) for MS have become available on the NHS. There are now 11 licensed DMTs for people with relapsing forms of MS. They can decrease the number and severity of relapses and slow the progression of disability. Added to this, there is now consensus among the MS and clinical community that early treatment with a DMT can improve long-term outcomes.

All figures related to DMTs are calculated among those who could benefit from these treatments (that is, those with relapsing remitting MS or secondary progressive with relapses).

Further treatments for MS are in development with some being considered for licensing and appraisal. It's possible there will be more DMTs available on the NHS from 2017 onwards. Daclizumab, for relapsing forms of MS, is being appraised for availability on the NHS. Two new treatments for primary progressive MS – biotin and ocrelizumab – are also currently being considered for appraisals by the National Institute for Health and Care Excellence (NICE). In Northern Ireland, the Department of Health (DoH) reviews NICE guidelines. If they decide the guidelines apply to Northern Ireland they endorse them for use in health and social care.

If these new treatments are successfully appraised, they will be the first DMTs available on the NHS for people with progressive forms of MS.

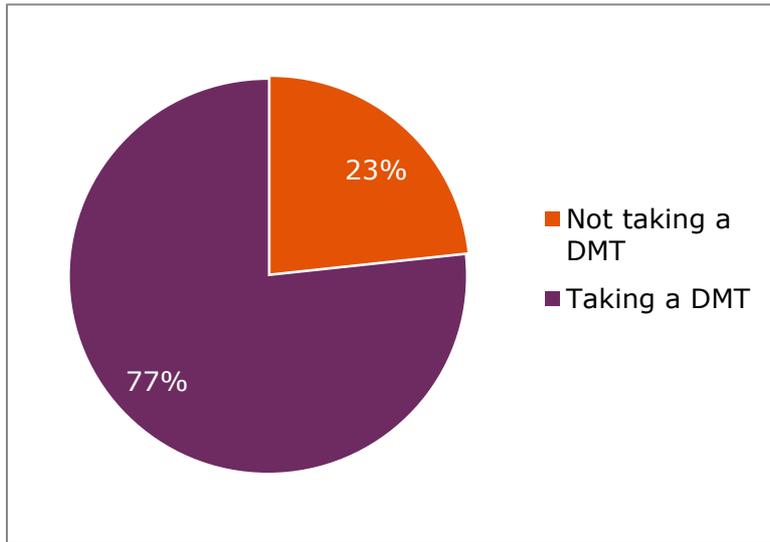
NICE are also appraising beta interferons and glatiramer acetate, the first DMTs which were made available for treating relapsing forms of MS.

With an increasing number of treatments available, it's even more important that people with MS are able to talk to an MS specialist about their options as soon as is appropriate after diagnosis. This is now agreed best practice – NICE recommends that, at the time of diagnosis, people with MS are offered written and oral information across a range of topics including DMTs.ⁱⁱ The Association of British Neurologists recommends that decisions about treatment should be jointly taken by the person with MS and their neurologist, with treatment starting as early as possible.ⁱⁱⁱ

In Northern Ireland, 77% of those who could potentially benefit from taking a DMT are doing so. People diagnosed recently are more likely to be taking a DMT than those who were diagnosed some years ago. 88% of those diagnosed between one and five years ago, and who could benefit from taking a DMT, are taking one, compared to

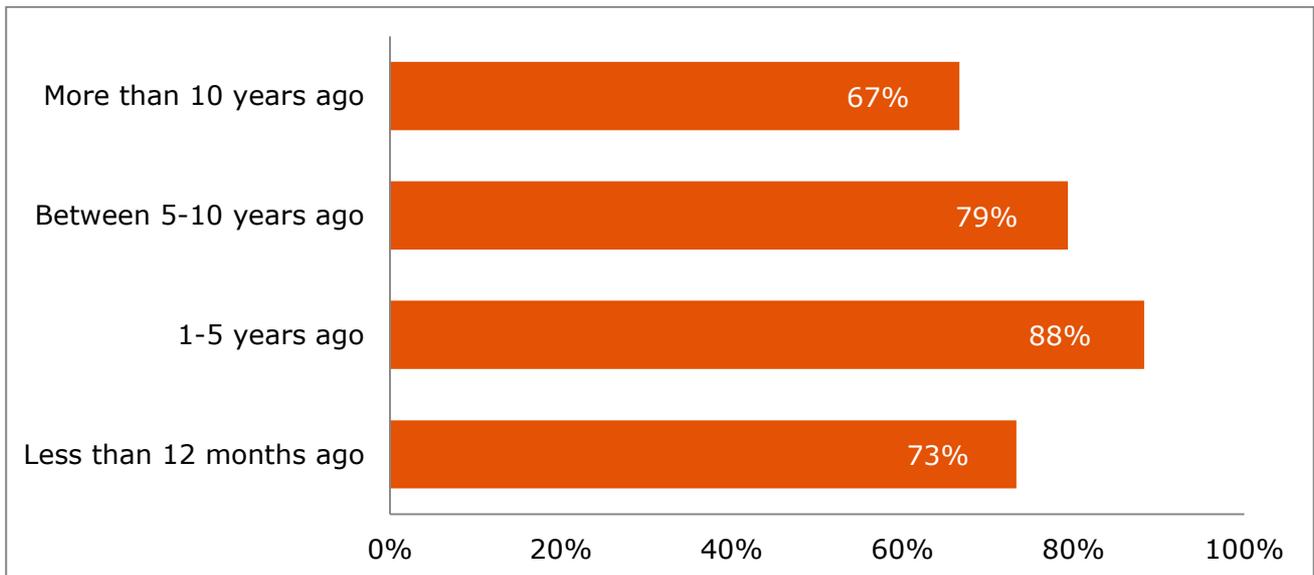
only 67% diagnosed more than 10 years ago. People are also more likely to be taking a DMT the younger they are.

Figure 2: Access to DMTs in Northern Ireland



There are several drivers that make it more likely that a person will be taking a DMT. Access to health professionals and the right information is key – 91% of people who have access to a neurologist, MS nurse and the right information and could benefit from a DMT are taking one. Just 33% of people who did not access any of these services are taking one.

Figure 3: Access to DMTs by time since diagnosis



Use of DMTs in Northern Ireland has increased since our last survey in 2013. This is to be welcomed. The increase is likely to be linked to the new treatments which are now available on the NHS, which are judged to be more effective and easier to take.

In the last year, the Health and Social Care Board has increased funding for DMTs from £10.256 million in 2013-2014, to £16.494 million in 2015-16. This ensures that all 11 treatments currently licensed for MS are widely available on the NHS in Northern Ireland.

Table: Access to DMTs in Northern Ireland, My MS My Needs 2 data

DMT	Count	Percentage
Aubagio	4	1.4
Avonex	27	10.0
Betaferon	5	1.9
Copaxone	29	11.0
Extavia	0	0.0
Gilenya	7	2.5
Lemtrada	6	2.1
Plegridy	4	1.4
Rebif	24	9.0
Tecfidera	74	27.7
Tysabri	26	9.9
Not taking any DMTs	62	23.3
Total	268	100.0

Table: Access to DMTs in Northern Ireland, Health and Social Care Board data, January 2016 data^{iv}

DMT	Count	Percentage
Aubagio	64	3.3
Avonex	333	17.4
Betaferon	59	3
Copaxone	275	14.3
Extavia	15	0.8
Gilenya	88	4.6
Lemtrada	29	1.5
Plegridy	42	2.2
Rebif	349	18.2
Tecfidera	529	27.6
Tysabri	136	7.1
Not taking any DMTs		
Total	1919	100.0

Increasing and evolving treatment options, each with different support and infrastructure requirements, have a profound effect on service models and delivery. This paints a complex, challenging picture when considered in light of the financial constraints of the NHS and professional caseloads already exceeding their optimum levels.^v

There are, of course, many examples of excellent MS treatment, care and support throughout the UK and beyond – we must learn from these and spread good practice if we are to meet these challenges.

Access to symptom management therapies

There are several symptom management therapies (SMTs) specifically licensed to treat MS, which can make a significant difference to the day-to-day lives of some people with MS. These treatments can help with problems such as spasticity and walking or an overactive bladder. Licensed SMTs for MS include Sativex, Fampyra and Botox, but none of these treatments are available through the NHS in Northern Ireland – although Sativex is available in Wales, and Botox is available in Scotland. Botox also received a positive recommendation within NICE guidance.

These treatments can be accessed through individual funding requests if the patient is considered to be an exceptional case. Only a small number of respondents in Northern Ireland are receiving Sativex (0.8%), Fampyra (2.1%) and Botox (2%). Certainly in the case of Sativex and Fampyra this reflects the difficulty many have in trying to obtain these SMTs through the NHS, due to the influence of the 2014 NICE guideline for MS, which does not recommend Sativex and Fampyra as cost effective treatments.

Fampyra is to be appraised by the Scottish Medicines Consortium (SMC) this year. We continue to campaign for all licensed MS treatments to be made available through the NHS in all parts of the UK.

Recommendations

- ▶ Conversations about treatment options, including DMTs, should begin close to diagnosis, with follow-up after diagnosis within six weeks and again within six months.
- ▶ Continue to increase the funding available for DMTs in Northern Ireland to ensure that all licensed treatments for MS continue to be available on the NHS in Northern Ireland.

Access to the right support

People with MS require access to professionals across all parts of the health and social care systems to best manage their condition. We believe that people with MS should have timely access to professionals and be at the centre of decision-making about their care.

Published earlier in 2016, the NICE Quality Standard for MS recommends that people with MS have access to care from a multidisciplinary team with expertise in MS.^{vi} This team should consist of a range of professionals including neurologists, MS specialist nurses, physiotherapists and occupational therapists, speech and language therapists, psychologists and mental health specialists, dietitians, social care, continence specialists and GPs.

Respondents to our survey were asked to indicate their need for and access to support from various professionals over the last 12 months.

MS nurses

MS specialist nurses play a crucial role in the care and support of people with MS. Their role and responsibilities can be wide-ranging and varied but typically include providing information and support on how to best manage MS and on DMTs, initiating and monitoring treatment for people with relapsing forms of MS, providing psychological support and co-ordinating care. People with MS regularly cite their MS nurse as their key contact for treatment, care and support.

Two-thirds of respondents (66%) had seen an MS nurse in the past 12 months. 21% had not but felt they had not needed to. Just over one in 10 (12%) had not seen a specialist nurse but felt they had needed to. We are concerned that one in 10 people with MS were unable to see a specialist nurse when they needed to – it is vital that the system has the capacity to be able to respond effectively to the needs of people living with MS.

Overwhelmingly people saw MS nurses in a specialist clinic in a hospital setting (86%). A smaller number saw a nurse in a community setting (2.5%).

Our survey data shows that the more recently a person with MS was diagnosed, the more likely they are to have seen a specialist nurse in the last 12 months – those diagnosed within the last 12 months are the most likely to have seen a specialist nurse (93%), compared to 59% of those diagnosed 10 years ago or more. In view of the traditional role that MS specialist nurses play in initiating and monitoring treatment with DMTs, it is perhaps unsurprising that access to specialist nurses and whether someone is on a DMT follow a broadly similar trend. People with more recent diagnoses are more likely to have seen a nurse or be on a DMT than those diagnosed some years ago.

There are seven MS nurses in the Belfast Health and Social Care Trust, two MS nurses in the Southern Trust and one full time and one part time MS nurse in the Western Trust. The South Eastern Trust recently recruited two MS nurses who will support the

consultant neurologist with an MS specialism in two dedicated MS clinics. There is a part-time community nurse in the Northern Trust however there continues to be no MS nurse within the neurology clinics in the Northern Trust. This results in an inequity of access to MS nurses across Northern Ireland, with people having to travel long distances to access treatments, advice and support. We continue to campaign to improve the MS nursing provision across Northern Ireland.

Neurologists

NICE recommend that everyone with MS should be offered a comprehensive review of their care at least once a year, typically including an MRI scan.^{vii} This review can be led by a neurologist but should draw on expertise from professionals across a multidisciplinary team. It should be tailored to the needs of the person with MS and cover symptoms, the disease course, general health, social activity, care needs and carers.^{viii} If a person is on a treatment, a comprehensive review could also be used to assess how that is working.

A high percentage of respondents had seen a neurologist in the last 12 months (82%). 7% had not, but felt they did not need to. One in 10 (10%) had not seen a neurologist but felt they needed to. 92% of people taking a DMT had seen a neurologist within the last year. 21% of people not taking a DMT reported needing to see a neurologist but not being able to.

Access to important MS services such as regular appointments with a consultant neurologist and an MS nurse is highly variable throughout Northern Ireland. MS services are struggling, resulting in long waiting lists, reduced quality of service, and impacting people’s quality of life.

Table: % of all referrals to Neurology waiting 18+ weeks for a first appointment across health trusts in Northern Ireland

Trust/Quarter	Q1 2015/16	Q2 2015/16	Q3 2015/16	Q4 2015/16
Belfast HSCT	65%	70%	73%	69%
Northern HSCT	54%	56%	64%	26%
South Eastern HSCT	50%	64%	67%	68%
Southern HSCT	52%	53%	60%	62%
Western HSCT	64%	67%	69%	63%
Northern Ireland	61%	65%	69%	65%

The solution to the long waiting times is to maximise the skills of neurologists who have expertise in MS by creating an MS Network for Northern Ireland. This will make best use of our highly skilled MS specialists, enabling more dedicated MS clinics in each Trust, improving patient outcomes and ending the wait for MS services.

People living with MS will have better access to neurologists with an expertise in MS. This includes access to urgent and review appointments and better access to other specialists such as MS nurses regardless of where they live and whether they are on treatment or not.^{ix}

We have outlined how this can be achieved in our paper 'MS: Voice for Change - End the Wait. Creating an MS Network for Northern Ireland', published in February 2016.

Some of the changes we suggest are organisational, with low financial implications. However there will need to be changes made to the job plans for existing consultants and an investment in a small number of new posts. There are junior doctors with a speciality in MS who are in the latter years of their training and will be able to address capacity issues in the near future. Neurologists with an MS specialism spend a greater proportion of their time on MS, therefore there needs to be an increase in the number of consultants to deal with non-MS neurological patients. The necessary infrastructure must be provided to support the high levels of DMTs for MS prescribed in Northern Ireland and increase access to MRI scans for people with MS. We are pleased that funding has recently been made available by the Health and Social Care Board for two new neurologists.

Professionals across the team

Survey respondents were also asked about their access to other types of support – physiotherapists, support to remain physically active, continence professionals, and emotional support. Building capacity across a multidisciplinary team is also a way of ensuring that people with MS can access the support they need.

Many people with MS experience bladder and urinary problems, including incontinence and infections. Continence advisers can provide people with MS information, for example about products and treatments for bladder problems, and confidential advice. Over a third of respondents to our survey (38%) had seen a specialist continence adviser in the past 12 months. 47% had not but felt they had not needed to. However, more than one in 10 (14%) people had not and felt they needed to.

In England in 2013-14, there were 23,665 non-elective hospital admissions for people living with MS which cost the NHS £43m. Urinary tract infections (UTIs) comprised 14% of emergency admissions.^x This data is not currently collected in Northern Ireland. A 2015 report by NHiS Commissioning Excellence and the MS Trust notes that a greater focus on anticipatory care, identifying at-risk patients and addressing issues before crisis point, could prevent many costly admissions and improve quality of life for many people living with MS.^{xi} Therefore it is both important for people with MS to receive specialist support when they need it, and potentially cost effective to provide such support to prevent emergency admissions further down the line.

Physical wellbeing

Services that support people with MS to remain physically active are important in helping people remain healthy and independent in their day-to-day lives. Research suggests that support to remain physically active has resulted in a decrease in GP and hospital consultant visits and reduced hospital bed days for people with MS.^{xii}

A quarter of respondents (26%) required support to remain physically active in the last 12 months but had not received any. 33% had received some form of support, but sources of this support varied – only 16% of all respondents received it from the NHS or their local health trust. 10% received support from a charity or voluntary organisation and 11% from somewhere else. This suggests that statutory services can play an increasing role in supporting people with MS to remain physically active.

51% of respondents had also seen a physiotherapist in relation to their MS. Again the sources of support from a physiotherapist also varied, with the largest number of people receiving support from the NHS (40% of respondents). 6% received physiotherapy through private health care, 9% through a charity or voluntary organisation and 1% through another source. 31% had not seen a physiotherapist in the last 12 months but indicated they did not need to. 17% had not seen a physiotherapist and felt they had needed to. As with support to remain physically active, this suggests a significant unmet need in the MS population.

Emotional support

Ensuring people living with MS can access emotional support is vital. Half of people with MS experience anxiety and half experience depression, with many experiencing both.^{xiii} There is a strong link between mental and physical health – a study in England found that, in 2012, £1 in every £8 spent on long-term conditions was linked to poor mental health.^{xiv}

As with support to remain physically active and physiotherapy, people received emotional support from various sources. More than one in five (22%) respondents indicated they had received emotional support in the last 12 months, with 17% of the total sample receiving it from the NHS. 4% received support from a charity or voluntary sector organisation, less than 1% through a private organisation and 2% from somewhere else. While 47% indicated they had not accessed emotional support and felt they did not need to, one in four (26%) had not accessed support and felt they needed to. In view of the strong links between mental and physical health, it is important that people with MS are able to access such services when they need them.

Recommendations

- ▶ People with MS should receive the same standards of care which meets nationally determined and recognised guidelines through the creation of an MS Network in Northern Ireland.
- ▶ People with MS should be offered a comprehensive review of their care at least once a year that draws on expertise across a multidisciplinary team.
- ▶ People with MS should be offered information and support at diagnosis to understand their condition and how it can be best managed. Their information and support needs should be reviewed regularly.
- ▶ People with MS should be offered support from a multidisciplinary team, including emotional support, continence advice and support to remain physically active.

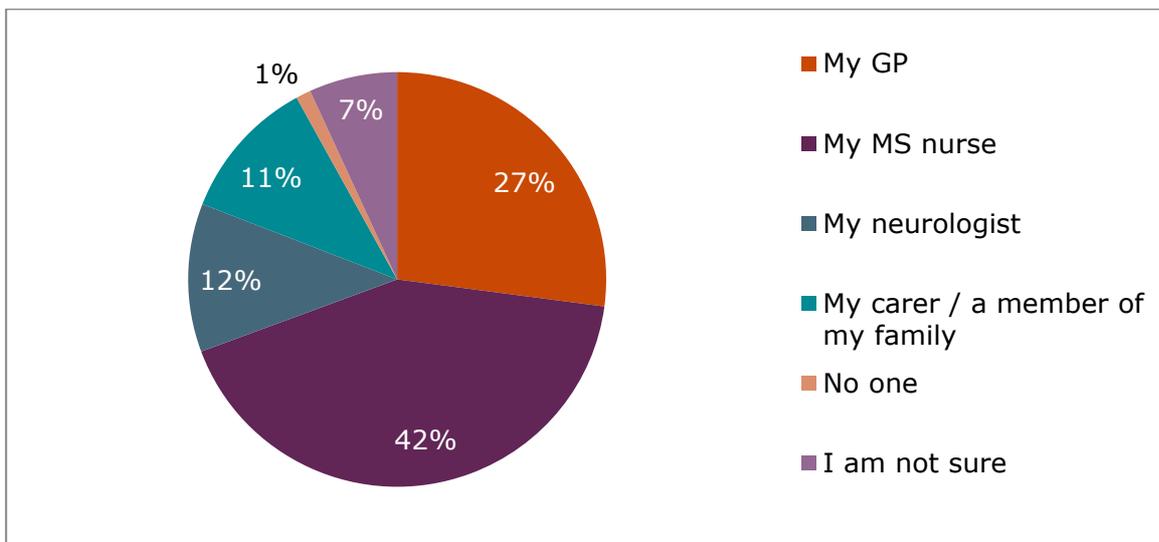
Care planning

Care planning and care co-ordination has a vital role to play in ensuring that people with MS can access the full suite of support they require to best manage their condition. NICE's Quality Standard for MS states that people with MS should have a single point of contact who then co-ordinates access to care across a multidisciplinary team.

For our respondents, the most common key contact for health care and support in relation to MS was a specialist nurse (42%), perhaps unsurprisingly given the typical functions of their role, followed by a GP (27%). People who listed their primary contact as a neurologist are most likely to feel they had their information needs on treatments met (71%), compared to those who listed a specialist nurse (69%) or GP (55%). This demonstrates the critical role that these health care professionals can play in helping people with MS make decisions about their care and treatment.

Worryingly, 8% of people said that no one currently performed this function, or they were not sure who did. 11% of people said a carer or member of their family performed this function – in this case, the degree to which that carer or family member has support from NHS professionals is unknown. NHS commissioners should consider whether bespoke care coordination roles in their area would allow more people with MS to have a key contact to help coordinate their care, while also relieving administrative pressures from specialist nurses.

Figure 4: Key contact for health care and support



Respondents were also asked whether they felt the professionals who helped plan their care worked well together. The most common response was "to some extent" (39%), while 15% responded "not at all" and 17% "completely".

We welcome the work that has been undertaken to date on creating a service specification for MS services in Northern Ireland. The draft service specification states: "services for patients with MS should be co-ordinated using a multidisciplinary

approach. Patients should have an appropriate single point of contact to co-ordinate care". The specification is closely aligned to the NICE clinical guidelines on the management of MS in primary and secondary care. The aims and objectives of the service specification clearly indicate what the MS service will deliver for people living with MS in Northern Ireland. At the time of writing we await its publication with an implementation plan and a clear timeline and budget.

In tandem with the modernisation of acute hospital services in Northern Ireland, the Department for Health in Northern Ireland wants to expand the range of care services that can be delivered in the community to support more people to live independent lives, preferably in their own homes. There is a drive to prevent unnecessary hospital admission, promote faster recovery from illness, support timely discharge, maximise independent living and improve the quality of assessment of long-term health and social care needs.

Despite this desire at a national level for personalised care and support, our survey found that, overwhelmingly, people living with MS in Northern Ireland had not been offered a care plan or care plan review in the last 12 months (78%). Only 11% of respondents had been offered a care plan and 6% offered a review.

Recommendations

- ▶ The MS Service Specification should be published with an implementation plan with a clear timeline and budget.
- ▶ People with MS should be offered a care plan or care plan review – this presents a key opportunity to involve people in their care.
- ▶ People with MS should have a single point of contact for their care, who coordinates care across a wider multidisciplinary team.

Recommendations

These results reinforce the need for concerted action to make sure that people with MS are able to access the right treatment at the right time, no matter who they are or where they live.

We ask that decision-makers take heed of our recommendations and work with the MS community to make them a reality:

1. People with MS should receive the same standards of care which meets nationally determined and recognised guidelines through the creation of an MS Network in Northern Ireland.
2. Conversations about treatment options, including DMTs, should begin as close to diagnosis as possible.
3. Continue to increase the funding available for DMTs in Northern Ireland to ensure that all licensed treatments for MS continue to be available on the NHS in Northern Ireland.
4. People with MS should be offered a comprehensive review of their care at least once a year that draws on expertise across a multidisciplinary team.
5. People with MS should be offered information and support at diagnosis to understand their condition and how it can be best managed. Their information and support needs should be reviewed regularly.
6. People with MS should be offered support from a multidisciplinary team, including emotional support, continence advice and support to remain physically active.
7. The MS Service Specification should be published with an implementation plan with a clear timeline and budget.
8. People with MS should be offered a care plan or care plan review – this presents a key opportunity to involve people in their own care.
9. People with MS should have a single point of contact for their care, who coordinates care across a wider multidisciplinary team.

Our commitment

We will use evidence and insight and work with others to support implementation of these recommendations by:

- ▶ Providing reliable information and support to enable people with MS to take control of their lives.
- ▶ Supporting people with MS to connect with other people with the condition.
- ▶ Funding the best, most relevant research to enable new treatments to reach people with MS as quickly as possible.
- ▶ Campaigning for fair and appropriate access to treatment, care and support for every person with MS.



References

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- ^{xiv} The King's Fund (2012) Long-term and mental health: the cost of co-morbidities. http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf (Accessed July 2016)

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.



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