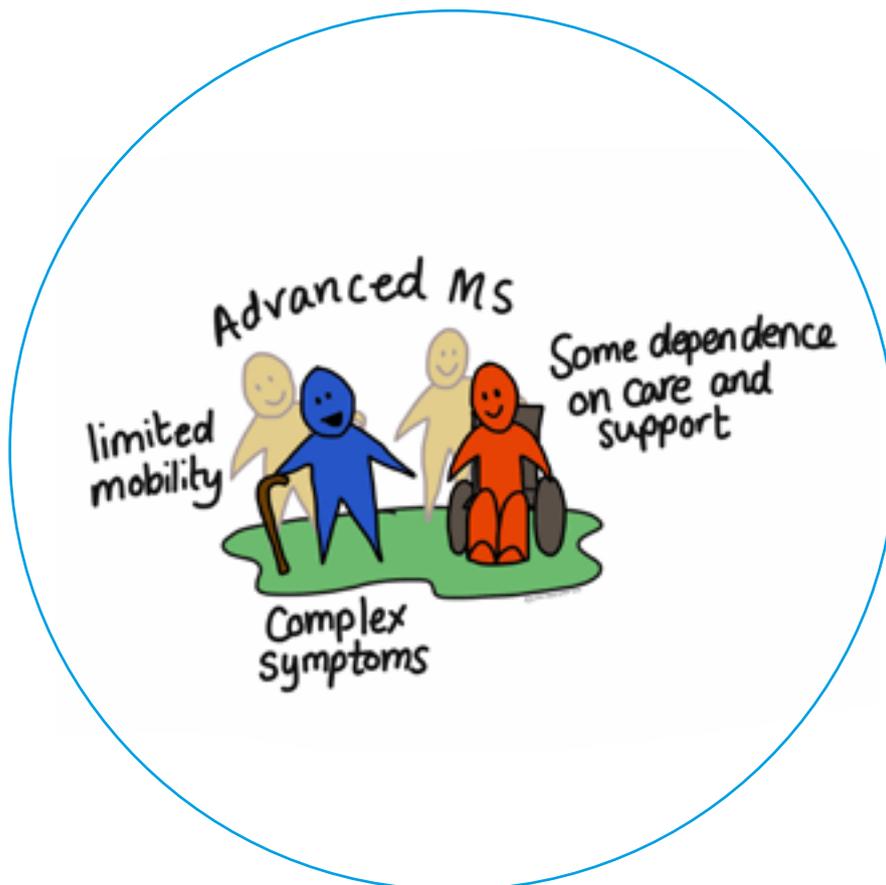




# Improving services for people with advanced MS

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Cover illustration by Clare Mills (Listen Think Draw).  
This image is a selection from the graphic facilitation of a workshop on care for people advanced MS.



## I Introduction: why focus on advanced MS?

Care of people with advanced MS is an area of specialist MS services that is often neglected. Overall demands on MS services are rising. There is a growing population of people with MS, a greater range of disease modifying drug (DMD) options, a move to earlier initiation of treatment and more switching or escalating to achieve optimum treatment response. Due to this increased focus on disease modification for people with early and relapsing MS, those for whom MS has already had a significant impact often struggle to get the care they need. In this context, many MS teams are finding it increasingly difficult to provide an equitable service for their whole caseload.

'Advanced MS' describes the scale of burden that MS is having on an individual, rather than the type of MS they have. People with advanced MS have:

- ▶ multiple, concurrent symptoms of MS which are ongoing
- ▶ dependence on others for some or all care and support needs
- ▶ significant impairment of function

Worsening of MS to a point at which it may fairly be described as 'advanced' is usually a gradual process, with increasing disability and worsening function developing over a number of years. Some individuals, however, may experience a rapid deterioration in their condition from diagnosis. Informal carers play a critical role in supporting people with advanced MS and supporting their needs is integral to providing a comprehensive model of care.

We have focused on advanced MS for three reasons:

- ▶ **People with advanced MS make up a significant proportion of the MS caseload.** There is limited data on the proportion of people with advanced MS at population level (not least because the definition is not clear cut), but a number of data sources\* suggest that 30–40% of people with MS have advanced MS, equating to 32,000–43,000 people in the UK.
- ▶ **People with advanced MS incur greater costs to the healthcare system.** Research shows that healthcare costs increase with additional disability, even allowing for the DMD costs incurred for people at an earlier stage in their MS<sup>1</sup>. In our GEMSS patient survey of 2014<sup>2</sup>, those with severe disability reported that they had spent an average of 13 more nights in hospital in the past year than those with minimal disability<sup>†</sup>.
- ▶ **People with advanced MS have less contact with MS services.** Previous research by the MS Trust indicates that those with relapsing MS who are on DMDs have more contact with MS services than others<sup>2</sup>. People with advanced MS are not eligible for DMDs and available service capacity is increasingly over-burdened with delivering the DMD pathway and the associated complex monitoring regimes. Many services recognise that team resources are being diverted away from those with advanced MS and the need to take corrective action to make their service more equitable for their whole caseload.

\* Analysis of an MS nurse representative caseload<sup>2</sup> shows that, taking everyone with 'severe' disability (Expanded Disability Status Scale score (EDSS) of 8 or more) and half of those with moderate disability (EDSS 6 – 7.5) gives 35% of the total caseload. An analysis of the Ontario cohort<sup>18</sup> shows that those with EDSS 6.5 – 10, plus half of those with an EDSS of 6, amounted to 38.5% of the MS population after five years in the study.

† Unpublished analysis.

**Box 1: Advanced MS and progressive MS: what's the difference?**

Progressive MS is defined in the medical literature as a gradual worsening with or without exacerbations<sup>3</sup>. Progressive MS is further described as either primary or secondary progressive depending on whether the gradual worsening is evident from disease onset or follows on from a relapsing remitting course. The rate of worsening is the same in both secondary and primary progressive MS.

Advanced MS, on the other hand, refers to the burden of the disease rather than the type of MS. People with a progressive form of MS may have advanced MS but not necessarily. They may still be mobilising independently, working and able to undertake most daily activities with minimal help. For those with advanced MS, however, their need for assistance in many daily tasks is greater and the support they need from services is correspondingly more complex. It is important to note that there will also be a small number of people with relapsing MS who have very active disease and, as a result of incomplete recovery from disabling relapses, may also be classed as having advanced MS.

People with advanced MS typically experience multiple, concurrent symptoms which include mobility and balance problems, weakness and spasticity, tremor and ataxia, bladder and bowel problems, sexual dysfunction, fatigue, cognitive symptoms, and psychiatric comorbidity<sup>4</sup>. They are also likely to need input from multiple agencies supporting people with complex disability, including community matrons and palliative care.



## 2 What did we do?

To better understand the main issues, we worked directly with people with advanced MS, their informal carers and those providing some of the healthcare services they need. We held a one-day workshop (see [Appendix 1](#)), bringing people together to discuss these issues and identify priority actions. We also used data from a range of other sources (listed in [Appendix 2](#)).

Input from people living with MS has been central to our work and our lay forum has helped us to get a broad understanding of the issues and concerns of those with advanced MS, their carers and families. More information about the lay forum is in [Appendix 3](#).

This report presents our synthesis of all these data and our findings and recommendations for how services can improve.

We recognise that the needs of people with advanced MS and their families are complex, ongoing and often constantly changing, and that these needs cross health and social care boundaries. The scope of this report focusses on the health needs of people living with advanced MS. Further work is needed to consider the broader issues in the integration of health and social care needs.



## 3 The starting point: how services currently work for people with advanced MS

There is no single model of service for people with advanced MS:

### 3.1 Hospital-based services

Some people with advanced MS remain with the same service from diagnosis onwards.

- ▶ The hospital-based MS service, with or without outreach clinics in the community, provides care for everyone with MS in their area.
- ▶ MS specialist nurses and neurologists usually work closely together and will typically share the care for everyone on the service caseload.
- ▶ In some services, allied health professionals with expertise in MS may also be co-located with the hospital team.
- ▶ The MS service will network with other healthcare professionals across their 'patch' (eg community-based allied health professionals, continence advisers, speech and language therapists, palliative care etc), coordinating referrals depending on need and availability of services.
- ▶ Hospital-based services are often more difficult to access for people with advanced MS and many lack the facilities needed to support outpatient review (eg equipment, time and training to allow people with MS to be hoisted in outpatient clinics).

#### **Box 2: A hospital-based multidisciplinary team**

##### ***Cardiff MS Nurse team, University Hospital of Wales***

The Cardiff MS team consists of five MS specialist nurses, a specialist physiotherapist, a specialist occupational therapist (OT), a psychologist, a neurologist, a research nurse and a small team to provide coordination and administrative assistance. They cover Cardiff and the valleys which is a mix of urban and rural geography.

The team works very closely together, to the benefit of people with MS in the Cardiff area. The whole team follows each person on the caseload from diagnosis, and initial contact is in the form of an MDT home visit by a team (consisting of an MS nurse, a physiotherapist and OT) at which point the patient is introduced to the service. The MS nurse works as their MS care coordinator. This visit is then followed up three months later by phone or email.

There is an MS nurse on call every day, to ensure that people with MS requiring guidance are more likely to reach a nurse sooner. An MS nurse, specialist physiotherapist, OT and psychologist hold monthly meetings about complex cases. The service uses a comprehensive database – 'Neurology Workstation' – which allows neurologists to easily communicate with the rest of the MDT, and referrals may be put through instantaneously.

By working in this way the MS service ensures that people with MS get to know the whole team well, and know who to contact and how. As a result, fewer cases are likely to get left 'off the radar' as people are followed up and have a close relationship with the team from diagnosis; even those people with complex and advanced MS feel supported by the relevant specialist health professionals.

### 3.2 Community-based services

Alternatively, people with advanced MS may have their care handed over to a separate community-based MS service.



- ▶ Community-based MS services may be part of a wider community rehabilitation service that includes allied health professionals with expertise in MS and MS nurses. It may also include those with expertise in other long term neurological conditions such as Parkinson's disease or motor neurone disease.
- ▶ Less frequently, MS nurses are based within the community nursing team in their locality and link in with a range of different services, including community rehabilitation teams.
- ▶ Joint working between community-based MS nurses and MS neurologists is variable, with some working closely and perhaps running some joint, hospital-based clinics, while others have only intermittent contact with MS neurologists who may not be based nearby.

Whatever the model, MS specialist nurses typically play a key role in coordinating and providing care. Access to neurorehabilitation physicians will vary, largely due to local availability.

Generally, medications to treat symptoms are prescribed by the GP, ideally though not always, in discussion with the MS specialist nurse, neurologist, or neurorehabilitation physician (if available). The MS nurse usually liaises with the GP and the person with MS to facilitate accurate prescribing.

Some teams will have regular, scheduled joint meetings of the multidisciplinary team (MDT) (see [Box 2](#) and [Box 3](#) for examples). As we explore later in this report, widespread use of joint meetings or formalised arrangements for multidisciplinary working is often not present within MS teams (see [Box 4](#) for more information about the characteristics of MDT working).

### **Box 3: A community multidisciplinary team**

#### ***Huntingdon Community MS Nurse Team***

The MS nurse team for Huntingdonshire is part of a community multidisciplinary team based within Cambridgeshire. They provide care for anyone with MS in the community, from people who are newly diagnosed to those with severe disability. There are two MS nurses who together to make up one full time equivalent post with a caseload of about 270 people with MS.

The MS nurses work very closely with the neurorehabilitation team and have regular joint meetings with them. The MS nurses also have regular meetings with the local palliative care team and with primary care services. Everyone on their caseload is offered a holistic annual review and has an individual care plan. People with complex needs have more frequent contact and support.

When they took over the MS service they found that a lot of people had been lost to follow up, particularly people with advanced MS. The MS nurses have established good networks with local GP practices ensuring they are all aware of their service and have asked GPs to refer anyone with MS back into their service; GPs are now proactively doing this and many of the people with advanced MS who had lost touch with the service have now re-engaged.

The MS nurses are able to offer a range of different appointment types including community-based clinics, joint MDT clinics for people with complex needs, virtual (telephone) clinics and home visits. This allows them to respond quickly and appropriately to meet people's needs. They have a proactive approach to care but are able to react to the needs of their patients as required.

The main goal of the service is to support people with MS in the area to manage their condition independently, to stay in their own home, to maintain a good quality of life and to manage symptoms as well as possible.



In England, MS care is the responsibility of a variety of different commissioning bodies, with most services funded via a mix of specialised provision commissioned by NHS England and local services commissioned by Clinical Commissioning Groups (CCGs). We explore the challenges of MS funding in England and its impact on service development in a separate report<sup>6</sup>. This lack of clarity does account, at least in part, for the variety of service models we see, as well as some of the operational challenges evident in making services seamless and efficient. For the other UK countries, while the challenges of commissioning don't apply in quite the same way, overall funding pressures are similar as is the drive to make service provision more seamless.

At our workshop and on the lay forum, people with advanced MS described how services work for them. They broadly reflected the types of models described above. Access to multidisciplinary services such as physiotherapy, occupational therapy or neuropsychology varied. Most, but not all, had access to an MS specialist nurse. Sometimes, however, people were wholly under the care of their GP with little or no contact with either an MS specialist service or a community neurorehabilitation team.

When asked about their needs, they all described living with a mix of ongoing and burdensome symptoms with intermittent, acute crises where a timely, appropriate response was essential to avoid unscheduled care such as an A&E attendance or worse still, a hospital admission. They all described a need for multidisciplinary support to help them deal with the range of symptoms and to help them manage their condition as independently as possible. Many raised the issue of wanting early access to palliative care to help with intractable symptoms, especially pain, and to have the opportunity to discuss and plan end of life care needs. We also heard about the importance of maintaining control over their life and choices, especially as disability increases. A recent study which mapped integration between neurology and palliative care services for different diseases found that this was the most limited in MS, with just two out of eight sites studied having regular, joint meetings<sup>7</sup>.



#### **Box 4: Multidisciplinary team working**

An MDT consists of healthcare (and possibly social care) professionals from different disciplines who use their combined knowledge, skills and experience to understand the needs of people with MS and plan and coordinate care to manage these needs.

As well as working together to meet the needs of people living with MS, an MDT will regularly meet to define, develop and review MS service provision. They will use their combined understanding and expertise to develop pathways and protocols which underpin the delivery of high quality, effective care to people living with MS.

An effective MDT should have an agreed set of common principles, one of the most important of these being a shared commitment to the delivery of person-centred, coordinated care from the perspective of the individual<sup>5</sup>.

The core MDT for people with MS will typically consist of an MS nurse, a neurologist and/or neurorehabilitation physician, a physiotherapist and an OT as a minimum; other health and social care professionals may well also be involved depending on who is available locally (eg neuropsychologist or speech and language therapist).

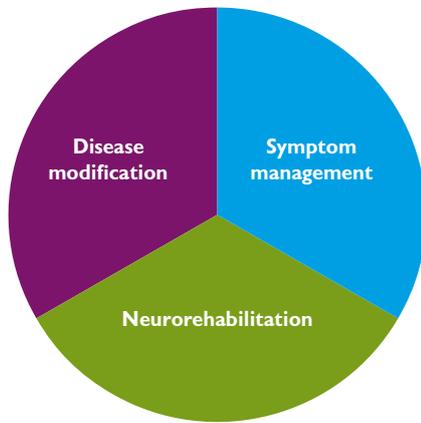
The core MDT will frequently liaise with a much larger network of other health and social care professionals from a much wider range of disciplines, sectors and potentially across organisational borders. This network will include roles such as continence advisors, district nurses, GPs, neuropsychologists, dieticians, palliative care services, wheelchair services, community matrons, orthotics etc. Care pathways and protocols developed by the core MDT should identify triggers which flag the timely involvement of the most appropriate health and social care professional from the wider network at the right time. Care delivered by the wider network will be coordinated by the core MDT and usually led by the healthcare professional who coordinates care for the individual with MS.

Whilst professionals within the wider network will not routinely be involved in regular MDT meetings, it is good practice to create opportunities for professionals involved in the care of people with MS to come together occasionally to review the overall service and participate in continuing professional development.

However a service is configured it should meet the needs of a person with advanced MS in terms of complex symptom management, preservation of functional ability and promoting self-management and independence. To achieve this, MS teams need to provide people with advanced MS with a blend of expertise from both MS specialist neurology and neurorehabilitation services. The need for skills and experience from both disciplines reflects the particular nature of advanced MS – a condition characterised by a complex interplay of difficult, often intractable symptoms, against a backdrop of progressive deterioration. It is worth noting that this is also consistent with many of the needs of the wider population of people with MS. Most, if not all, people with MS deal with a very individual set of difficult, ongoing symptoms. Any comprehensive MS service, configured for the needs of the whole caseload from diagnosis and throughout the disease course, will need to provide a flexible blend of disease modifying treatment, symptom management and neurorehabilitation (see [Figure 1](#)).



Figure 1: Three core elements of holistic MS care



**Symptom management:** Interventions which aim to alleviate the symptoms of MS, prevent complications, recognise comorbidities and mitigate the risk of side effects from medications. Provision of palliative care is an important component of symptom management.

**Neurorehabilitation:** A process of assessment, treatment, management and evaluation by which the individual with MS and their family/carers are supported to achieve and maintain their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living<sup>8</sup>.

**Disease modification:** Drug treatments which lessen the impact of the disease course for individuals with active disease.



## 4 The barriers to improving services

We identified a number of barriers to improving services for people with advanced MS. Many of these are historical, with roots in an increasingly out-moded, medical model of MS care where there was little to offer someone with advanced disease. Many barriers, however, are symptomatic of pressures that are evident across the NHS, where demand and capacity are poorly matched and those with complex needs who require services that cut across settings and sectors often fare worst. These are outlined below:

### 4.1 People with advanced MS are at particular risk of becoming disconnected from MS services

Research by the MS Trust highlights that people with advanced MS can become disconnected from or even lost to MS services and many of them will be managing multiple MS-related symptoms without access to specialist input<sup>9</sup>. This issue of losing touch with the MS team is echoed in the findings from the MS Trust's [Is MS Care Fair?](#) survey and in feedback from participants in the workshop and by the lay forum.

There are several reasons why people with advanced MS are more likely to lose touch with MS services:

#### 4.1.1 Many people with advanced MS will have previously been on DMDs.

When DMDs are stopped people can lose touch with services, often due to the mistaken belief that nothing further can be done<sup>‡</sup> or that the service has lost interest in them.

*“When I had relapsing remitting MS I was under the care of a neurologist and MS specialist nurse and took a DMD. Now that I am secondary progressive, I have been discharged from that care and referred to my GP – nothing else has been offered.” (Is MS Care Fair? survey, 2016)*

*“All of a sudden you get a feeling that you are no longer on the radar and that in some respect you’ve been abandoned by those that were previously involved with you.” (Is MS Care Fair? survey, 2016)*

*“Although I am not yet classed as having advanced MS it is something which I will inevitably face. What I have noticed is the distinct lack of any emotional support from point of diagnosis and beyond.” (Lay forum member)*

*“There is no treatment for people with progressive MS, but little awareness that, because of this, we need more, not less, intervention from healthcare professionals.” (Is MS Care Fair? survey, 2016)*

As their condition becomes more advanced, people with MS report that contact with their neurologist may reduce or stop altogether<sup>10</sup>. The results of the [Is MS Care Fair?](#) survey showed that people with progressive MS<sup>§</sup> are much less likely to have seen either the consultant neurologist (55% vs 79%) or the MS nurse (60% vs 79%) than people with relapsing MS in the previous 12 months. They were also twice as likely not to have seen any MS specialist healthcare professionals. Other healthcare professionals are likely to have been involved in their care during this time but this doesn't obviate the need for MS specialist input.

In the MS Trust's recent survey of neurologists<sup>17</sup> it was evident that neurologists continue to follow the majority of people with MS throughout the whole trajectory (see Figure 2); however this is not always the case. Neurologists reported that they may also refer people on to another service, but this may be problematic

- if it isn't clear who is now leading their care
- if there is poor or non-existent coordination between the MS specialist team and the other teams

‡ Responses to the [Is MS Care Fair?](#) survey (2016), from individual lay forum members via the closed Facebook group and at the advanced MS workshop.

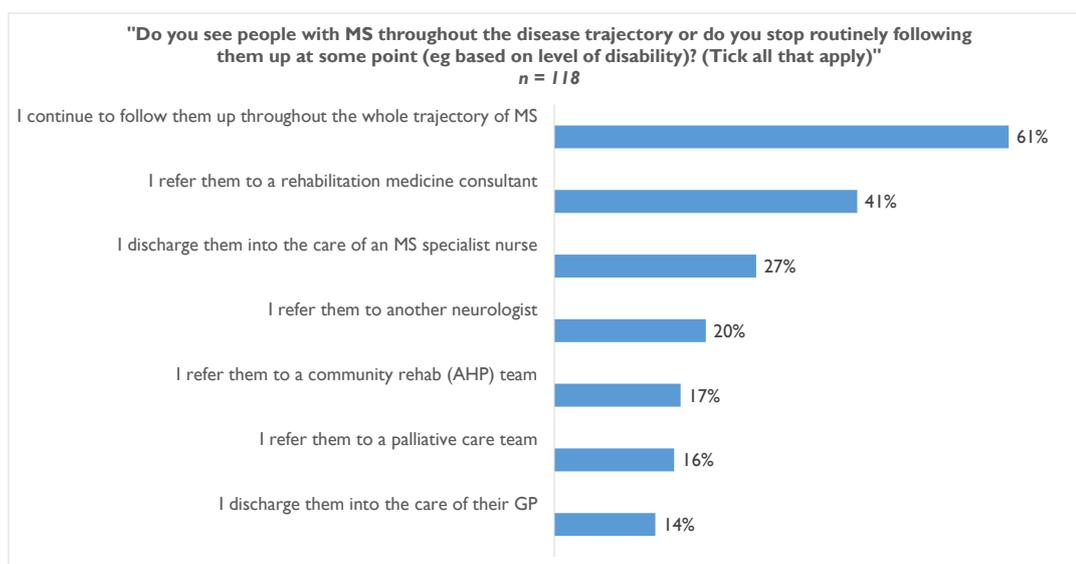
§ Respondents to the survey were asked to define their MS in terms of whether it was classed as primary progressive, secondary progressive or relapsing remitting; see [Box 1](#) for more information about how progressive MS relates to advanced MS.



- ▶ if the person with MS doesn't clearly understand what service they are now receiving, how the MS specialist team will be involved and who should be their main point of contact.

Some people with advanced MS who are not followed up by a neurologist may be discharged only to the care of their GP. This is not appropriate for anyone with MS and risks there being no specialist input into their care. There will also be no mechanism for an annual review by a health professional with expertise in MS, as recommended in the NICE MS clinical guideline<sup>11</sup>.

Figure 2: Follow-up patterns reported by MS neurologists (MS Forward View survey of 118 neurologists, 2016)



#### 4.1.2 People with advanced MS may have difficulty accessing hospital appointments.

This may be due to problems with mobility, fatigue or other difficult symptoms; frequent attendance at appointments also increases the burden on carers. If there is no alternative, such as home visits or community outreach clinics, people living with advanced MS may lose heart and prefer not to attend rather than deal with the difficulties. Services themselves may accept that and allow for contact to dwindle.

*'Patients with progressive MS who are unable to come to the appointments because of mobility problems and whose condition is stable with no need for further medication changes are given open appointments or told to ask their GP to re-refer if issues arise.'* (MS neurologist<sup>17</sup>)

#### 4.1.3 People with advanced MS are often not clear about what services are available to them.

Many said they did not have information about what the MS service offers people with their needs. The workshop participants described:

- ▶ being unclear about whether they were still part of the MS service or not
- ▶ feeling that any service for advanced MS was, in effect, 'bolted on' to an MS service for those on DMDs and isn't suited to their needs.

*"If we had this information [which services are available and what they can offer] available to us, I'm sure it would be cost effective. We wouldn't need to take up GP time, MS nurse and neurologist time in order to be seen by the correct service. Often, even GPs don't know what specialist services are available and what information they do have is out of date. This means long waits and possibly inappropriate referrals before we end up back at*



*square one. However, all of this would be helped along if the neurology department and MS nurses had more interest/care about treatments/services for progressive MS in the first place.” (Lay forum member)*

## 4.2 MS service models are skewed toward the needs of people on disease modifying drugs

Over the last 20 years, services for people with MS have developed significantly but this has largely been driven by the needs of people with early and relapsing MS. This is principally due to improved diagnostic criteria and the advent of DMDs introduced in the late 1990s. DMDs are currently only available for people with relapsing MS and help to reduce relapse rate and lesion accumulation (evident on MRI), they may also slow progression of disability as well as potentially improving long term outcomes for some people<sup>12, 13</sup>.

Many of the DMDs require different, complex monitoring regimes that need an increasing amount of specialist time and resources to implement safely. There is also greater emphasis on early initiation of DMDs reflected in the latest prescribing guidance from the Association of British Neurologists (ABN)<sup>14</sup>. As a consequence, service development has, by necessity, been driven disproportionately by the DMD pathway, with neurologists playing a central role and services being based predominantly in hospital outpatient settings with a strong focus on selection, administration and monitoring of DMDs.

There is no doubt that DMD administration and management is a critical element of any MS service. However, those eligible for DMDs only make up around half of an MS nurse caseload<sup>2</sup>. The increasing amount of specialist MS nurse and neurologist time and resources required to deliver safe and effective DMD regimes has two principal but unintended effects:

- ▶ the needs of those who are not eligible for DMDs may be, in effect, demoted as service capacity is absorbed by delivering the DMD pathway.
- ▶ the holistic needs of everyone with MS (including those on DMDs) for symptom management, self-management support and neurorehabilitation may not be addressed adequately by over-stretched services.

## 4.3 Multidisciplinary services are patchy or insufficient in many areas

The MS Trust’s recent report on MS nurse provision in the UK shows that around two thirds of people with MS live in areas where the caseload per MS nurse is greater than the sustainable level of 358 people with MS per MS nurse<sup>16</sup>. The report also highlights the paucity of administrative support for MS nurses, which eats further into their time for face to face patient interaction. A recent report by the ABN also highlights the shortage of neurologists across the UK. The recommendation is for one neurologist per 70,000 people and there is currently approximately one neurologist per 100,000 people<sup>19</sup> which suggests a shortfall of 279 across the UK<sup>¶</sup>.

It is not only MS nurse services and neurologists that are under resourced. Results from the survey of neurologists<sup>17</sup> and of MS nurses<sup>16</sup> both show that provision of neurorehabilitation services across the whole UK is very patchy, insufficient or, in some cases, non-existent (see [Figure 3](#)).

¶ Estimated UK population of 65,111,000.



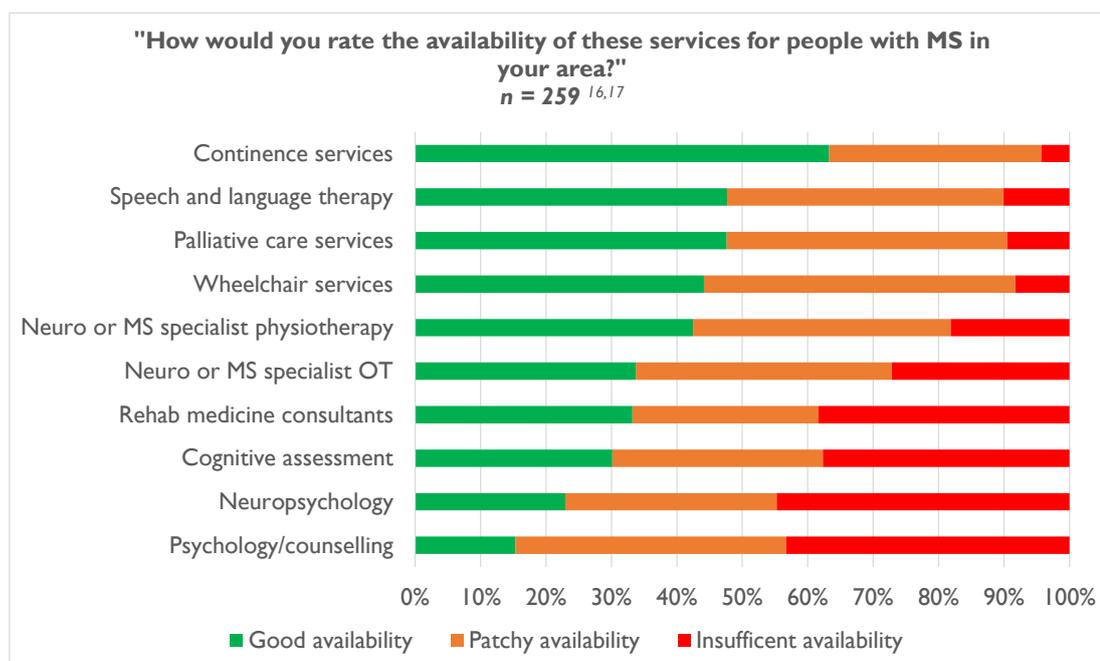
Neurorehabilitation physicians are an even scarcer resource with only a third of MS specialists reporting 'good' availability in their area. Neurorehabilitation physicians expressed a clear wish to be more involved in the care of people with MS whilst noting capacity is an issue.

*"I suspect most services like my own have worked hard to improve efficiency, but a point is reached where no more can be done without an increase in staff. There must be an expansion of neurorehabilitation teams with specialist expertise." (Neurorehabilitation physician<sup>15</sup>)*

Nearly three quarters of neurorehabilitation physicians report that they spend less than 40% of their time on MS and almost a quarter (23.3%) report that they have to discharge people from their caseload due to capacity constraints (n=60)<sup>15</sup>. It is unlikely with current resources that the care of people with advanced MS could be transferred to a neurorehabilitation physician. The more likely model is that they will be involved on an episodic basis, with transfer of care only in individual cases.

Worryingly, psychological support for people living with MS is particularly under resourced with almost 45% of MS specialists reporting that these services are insufficient in their area<sup>16, 17</sup>.

Figure 3: Availability of key multidisciplinary services across the UK





#### 4.4 There are often poorly defined pathways and protocols integrating different teams into one seamless service

As we have described earlier, holistic MS care relies on a mix of disease modification, symptom management, and neurorehabilitation (see [Figure 1](#)). Those with advanced MS have a particular need for the latter two. It is also important for MS services to be aware of any other conditions which the person with MS is living with. The prevalence of comorbidities in MS is difficult to ascertain with any accuracy but there is increasing evidence that comorbidities are associated with delays in diagnosis, progression of disability, health-related quality of life and progression of lesion burden on magnetic resonance imaging<sup>20</sup>.

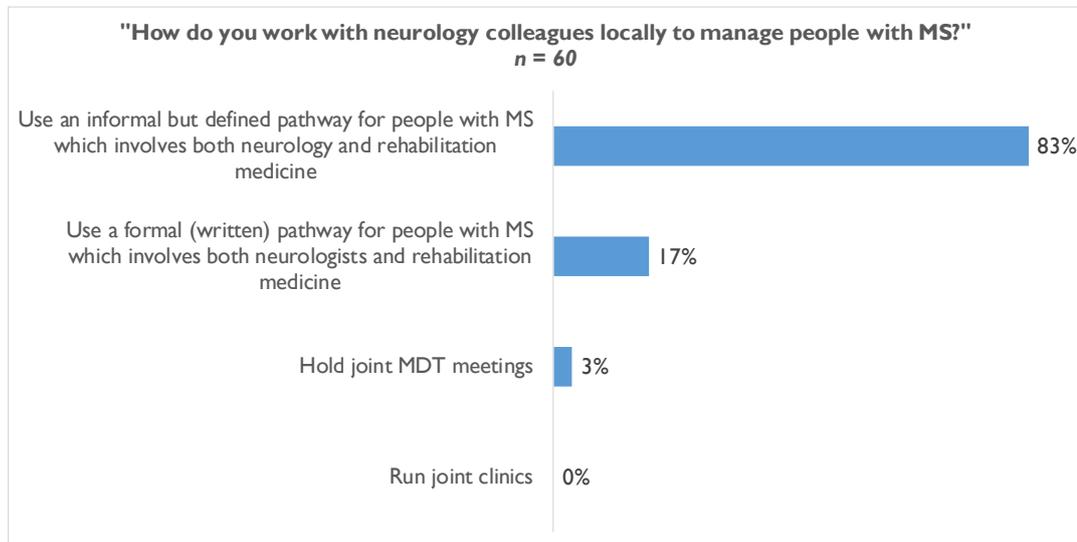
To accommodate such an integrated model and ensure the interface between different elements works in a coordinated way requires more than the informal agreements that often characterise current service delivery. Our recent survey of neurorehabilitation physicians reveals that the vast majority rely on informal arrangements and very few participate in joint meetings with the MS service, the cornerstone of a truly multidisciplinary culture<sup>15</sup>.

Regardless of whether services for people with advanced MS are based in the community or hospital, local networks with other services providing care for people with MS are a core component of holistic MS care – no single service can possibly provide the range of expertise people living with MS are likely to need. The majority of MS services do currently have good networks with other service providers in their locality, however these networks are largely informal and often rely on goodwill between particular individual healthcare professionals rather than more robust, formalised care pathways and protocols. Whilst setting up formal pathways and protocols does require some investment of time by healthcare professionals from the different services initially, people with MS benefit as services are much better integrated and not reliant solely on particular individuals being in post.

Joint working between MS nurses and neurologists is widespread and well-established. Our MS nurse survey shows that around two thirds of MS nurses regularly meet with neurologists and at least one other MS health professional<sup>16</sup>. Where there is only one MS nurse in the team, this figure falls to around 50%. However, only 3% of neurorehabilitation physicians report holding joint meetings with neurology colleagues and less than a fifth work to a formalised pathway (see [Figure 4](#)). The majority of neurorehabilitation consultants (n=15) highlighted the need to establish more formal arrangements and to improve care pathways<sup>15</sup>.



Figure 4: How neurorehabilitation consultants work with neurologists<sup>15</sup>

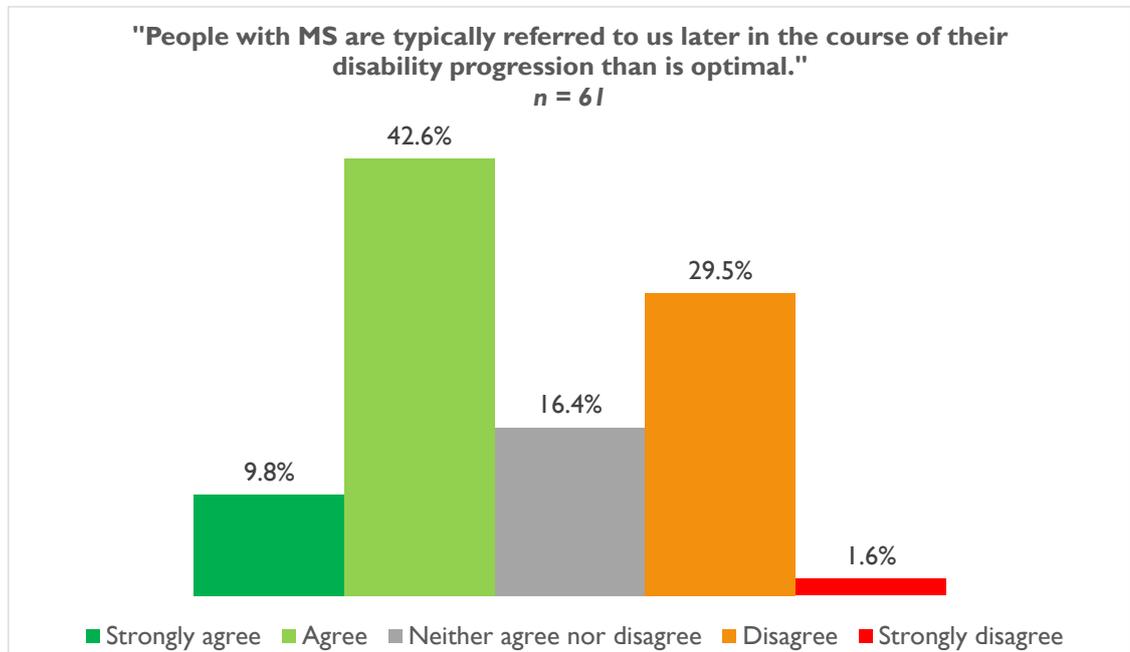


What is less clear is the optimal time for involvement of neurorehabilitation physicians (see [Figure 5](#)). Though around half of neurorehabilitation physicians felt there was scope for earlier referral, a third disagreed<sup>15</sup>. As a scarce resource, their contribution needs to be well-timed. Further work is required to define timely referral and identify triggers for their involvement. The approach and culture of neurorehabilitation, however, could be more fully incorporated into MS service models through training and improved pathways with a greater focus on early intervention to maintain function, help people stay in employment and to promote physical and psychological resilience. Early referral to allied health professionals working within neurorehabilitation teams, such as physiotherapists or OTs specialising in MS, should not depend on the availability of a neurorehabilitation physician.

*“People with MS should be referred early to neurorehabilitation services irrespective of their degree of disability. There should be an MS care pathway with neurorehabilitation medicine being a core part of the service.”*  
(Neurorehabilitation consultant<sup>15</sup>)



Figure 5: Half of neurorehabilitation physicians felt there was scope for earlier referral<sup>15</sup>





## 5 Where to go from here: priorities to improve services for people with advanced MS

In this section, based on what we have learned, we identify a set of priorities to help MS teams improve the care of people with advanced MS. To make these a reality and to promote overall service equity, the first priority is that

**Every MS team should have a named professional lead for advanced MS. People with advanced MS and those who care for them have a particular need for coordinated care from a wide range of services. For many, this includes timely access to palliative care. The lead for advanced MS should be responsible for involving the wider network of services, developing care pathways and making sure people with advanced MS know what services are available to them.**

Throughout this project, we considered whether there is an ideal service model for people with advanced MS. The consensus of the lay forum and the workshop participants is that the model of care is less important than the core characteristics of the service. Based on what we have learned,

Everyone with advanced MS should

- know what role they play in their own care and how the service will support them to make the choices that are right for them.
- receive written information about how the MS service works for them. This should include the name of the healthcare professional who will coordinate their care, how to contact the service and how a neurologist and/or neurorehabilitation consultant will be involved.
- have a named MS specialist healthcare professional who will coordinate their care, typically an MS specialist nurse or, in some cases, an allied health professional with expertise in MS. The named MS specialist should take a leading role in ongoing management, involving the neurologist and/or neurorehabilitation consultant as required, for example, where there are complex drug interactions or difficult interplay between symptoms or comorbidities.
- be offered an annual review with their MS specialist healthcare professional or someone else in the multidisciplinary team with specialist expertise in MS and should know how to access services in between appointments if need arises.
- have a personalised care plan developed in conjunction with the MS specialist healthcare professional who is coordinating their care and in collaboration with the multidisciplinary team.

Every MS service should

- have outcome-focused service aims that are appropriate for their entire caseload, are centered on the person with MS, drive early involvement of rehabilitation and a proactive multidisciplinary culture. From this project and other work by the MS Trust, we recommend, as a starting point that a comprehensive MS service aims to:
  - Minimise disease impact
  - Optimise function
  - Maximise self-management
  - Promote well-being
  - Avoid complications
  - Recognise comorbidities
  - Support shared decisions
- have a service specification that clearly defines how services for people with advanced MS are provided



and how carers are supported. The service specification should make clear how the MS specialist and neurorehabilitation teams will work together and involve wider services such as palliative care.

- ▶ communicate and market the service specification to people with MS, carers and other services and work with managers and commissioners to use the service specification as a lever for improvement.
- ▶ offer alternatives for people with MS who find it difficult to attend hospital clinic appointments.
- ▶ implement formal pathways to trigger involvement of neurorehabilitation and ensure multidisciplinary working, including joint meetings to make care decisions and coordinate timely involvement of other services, such as palliative care and primary care.
- ▶ provide training for the multidisciplinary team and other health and social care professionals about the needs of people living with advanced MS and best practice in multidisciplinary working.

In addition, there are several issues that individual teams should consider as part of their advanced MS service review:

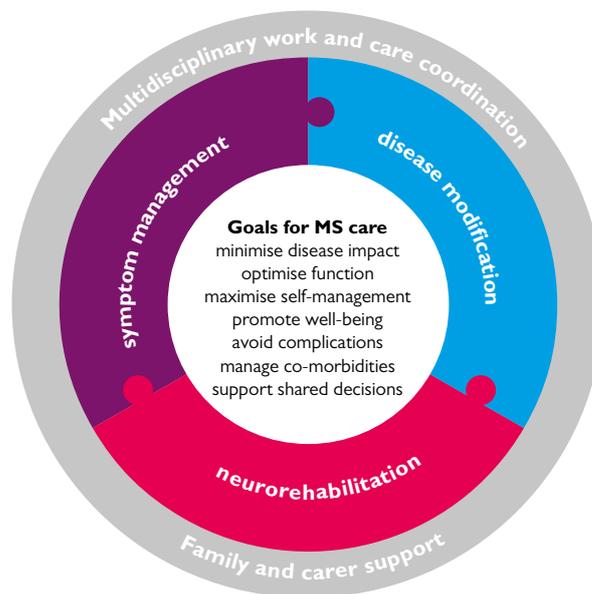
- ▶ whether independent prescribing of symptomatic treatments by MS specialist nurses and/or allied health professionals with expertise in MS, supported by clear protocols, is a facilitator of improved services for people with advanced MS. It may enable more efficient management of whole episodes of care and reduce reliance on GPs to prescribe symptomatic treatments.
- ▶ how their current home visit policy affects people with advanced MS, this is likely to be particularly relevant for hospital-based teams where there are often more restrictions on home visits and travel distances may be greater. Being able to offer a home visit and being able to visit people with MS in residential care homes when needed is an essential part of a responsive service for people with advanced MS.



## 6 Conclusion

The profile and needs of people with advanced MS need to be reasserted and MS teams need to make improvements in this part of their service a priority. Another report from the MS Trust MS Forward View project recommends ways to improve the DMD pathway, make more efficient use of resources and create capacity in their service<sup>21</sup>. It is imperative that any capacity which may be created is reinvested towards improving care for everyone with MS. In particular, there is a need to embed the culture and practices of neurorehabilitation more fully into MS services (Figure 6).

Figure 6: A multidisciplinary model for MS care





## Appendix I: The advanced MS workshop

A full day workshop was held in Birmingham on 17 May 2016. A graphic facilitator helped to record the outputs from the day.

### Delegates

A range of different healthcare professionals from around the UK and people living with MS attended:

- ▶ Three members of the MS Forward View lay forum (two people with MS and a carer of someone with advanced MS)
- ▶ Neuro specialist physiotherapists from a range of different services
- ▶ MS nurses based in a range of different services including the voluntary sector
- ▶ MS neurologist
- ▶ Neuro specialist occupational therapists
- ▶ Neurorehabilitation nurses

Invitations were also sent to neurorehabilitation consultants and to GPs with a special interest in MS but none were able to attend on the day.

A total of 18 delegates attended on the day; delegates were split into three groups and worked in these groups for the duration of the workshop.

### Workshop programme

The workshop started with a presentation setting out the available data about the provision of services for people with advanced MS. Responses from the lay forum had been collated in advance and were presented to the group by a member of the lay forum.

Delegates were asked to participate in a number of activities during the day:

- ▶ identify the features of a high quality service (brain storming)
- ▶ identify current barriers to delivering good care (group work and whole group discussion)
- ▶ identify enablers of different models of care (group work and whole group discussion)
- ▶ develop an 'elevator pitch' for a commissioner – developing a statement to describe a high quality healthcare service for people with advanced MS (group work, 'dot democracy' voting and whole group discussion)
- ▶ discuss burning questions (whole group discussion)

### Burning questions

A series of five 'burning questions' were presented to delegates on the morning of the workshop and reviewed again by the whole group towards the end of the day:

#### **1. How important is it that a person with MS remains under the care of one team or one MS specialist nurse throughout the course of their life?**

Having one point of contact from diagnosis to end of life works well if care is available to meet changing needs along the pathway. Having someone you know and who knows you is a big advantage but more



important is getting the care that you need when you need it. If it is necessary to transfer to another team at some point the transfer must be seamless.

**2. Should people with advanced MS remain under the care of a neurologist, or might it be better for their care to be led and coordinated by someone else, who could be a neurorehabilitation medicine consultant, allied health professional with expertise in MS or MS specialist nurse?**

Delegates agreed that care does not need to be under the care of a neurologist or neurorehabilitation consultant but should be led by an MS specialist nurse or therapist with appropriate levels of competence and experience. Access to a neurologist and neurorehabilitation consultant should be available to all whenever it is required.

**3. Do people with advanced MS have more in common with people with other neurological conditions than with people with relapsing remitting MS, and does this influence the best models of care?**

Whilst there is an overlap between the needs of people with early and relapsing MS, advanced MS and other long term neurological conditions, delegates agreed that people with advanced MS may be better served in terms of service design and delivery if we consider different groups/cohorts of people and design services specific to their needs.

**4. There are many models of care in operation for people with advanced MS. Should we recommend one as best practice, or can all work with the right conditions in place?**

Delegates agreed whilst there is no single 'best' model of care there are key elements which would be found in a high quality service which teams should seek to include within their service provision.

**5. As and when a disease modifying drug for progressive MS becomes available, does this influence how care should be delivered?**

Whilst we welcome the availability of a DMD for people with progressive MS, delegates agreed that it is unlikely to be relevant to people with advanced MS.

**'Elevator pitch': The features of a high quality service for people living with advanced MS**

A statement summarising the features of a high quality service for people with advanced MS and their families was developed by delegates at the workshop:

**A user led, responsive and coordinated service providing complex, holistic care when and where people need it. The service minimises unscheduled attendances by working with family and carers to meet changing needs and optimise health outcomes in a cost effective manner.**



## Appendix 2: Data sources

Data sources used within MS Forward View	Notes
Consultant neurologists and MS survey, 2016	<p>Online survey in conjunction with the Association of British Neurologists (March-July 2016).</p> <p>83 MS specialist neurologist respondents</p> <p>35 respondents who see people with MS, but aren't MS specialists</p>
Evidence for MS specialist services: findings from the GEMSS MS specialist nurse evaluation project, 2015	<p>GEMSS (Generating Evidence in MS Services) is an MS Trust national programme of work to help health professionals working in MS evaluate and improve their services and to demonstrate what works best to meet the needs of people with MS.</p> <p>Working with the MS Trust GEMSS facilitators, two cohorts totaling 15 teams collected service and user experience data over one year.</p> <p>The teams had a combined caseload of over 15,000 people with MS. This represents approximately 12-15% of people with MS in England and Scotland.</p>
Is MS care Fair? survey, 2016	<p><a href="#">MS Trust online survey</a> for people with MS about their experience of MS care (February-March 2016).</p> <p>1,857 respondents</p>
Lay forum feedback	<p>Work of the lay forum is detailed in <a href="#">Appendix 3</a></p>
Neurorehabilitation consultants and MS survey, 2016	<p>Online survey run in conjunction with the British Society for Rehabilitation Medicine (February-March 2016)</p> <p>80 consultants completed the survey, of which 67 regularly saw people with MS and we have only used their responses in the data analysis.</p>
MS specialist nursing in the UK 2016: progress toward equitable provision	<p><a href="#">A survey of all 168 MS nurse teams</a> in the UK (February-July 2016).</p>



### **Appendix 3: Role of the MS Forward View lay forum**

The MS Trust has developed a forum of people with MS and carers. The aim of the forum is to:

- ▶ represent the views and experiences of people with MS
- ▶ help keep the project team focused on the needs and views of people with MS throughout
- ▶ hold the project team accountable to ensure that the intended outcomes of the project are relevant to and resonate with people with MS

Three volunteers were recruited to represent the forum on the advisory group. The forum itself consists of approximately 60 people living with MS. The majority of this group communicate via a closed Facebook group. A smaller number prefer not to use Facebook and communicate via email.



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## About MS Forward View

MS Forward View is a one year project, launched in November 2015, to identify the priority actions needed across the MS sector to enable MS services to deliver efficient, effective and equitable services for everyone with MS, in the context of changing treatment paradigms. MS Forward View is looking at how MS services can make better use of current resources and skills, and how best to measure the quality and equity of access to services for everyone with a diagnosis of MS. We are bringing together clinicians, specialised and local commissioners, professional bodies, experts in workforce planning, multidisciplinary educators, people with MS and patient organisations, to produce a sector-wide consensus on how to optimise the provision of equitable, evidence-based care for everyone with MS. This plan will also help define future education programmes for health professionals working in MS.



## About the MS Trust

The MS Trust is a charity which works to make a difference today for the more than 100,000 people living with MS in the UK.

We work to make sure everyone affected by MS can access good quality, specialist care. We do this by providing high quality education and professional development support to MS specialist health professionals so they can deliver an even better service. We support health professionals with online information, publications and updates on the latest research.

Through our innovative GEMSS programme, we support evidence-based service improvement in MS care. Our approach is always to work in partnership with health professionals to improve MS services now and in the future.

We also produce practical, reliable information for people living with MS. Our information is available online and in print, and we offer a telephone and email enquiry service to anyone who needs to know more about MS. Our materials are widely used by MS services across the UK.

We receive no government funding so we rely on donations to fund our vital services.

To find out more about our work, how we can help you and how you can get involved

Visit [www.mstrust.org.uk](http://www.mstrust.org.uk)

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