RETHINKING MS IN EUROPE

Prioritising integrated services for people with multiple sclerosis

EBC European Brain Council

The Health Policy Partnership
[research, people, action]

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For more information on RETHINKING MS, please visit:
www.braincouncil.eu/RethinkingMS

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FOREWORD

Multiple sclerosis (MS) is a neurological disorder that exists at a critical intersection of healthcare, social welfare and employment policies. As a chronic neurodegenerative condition with onset at a young age – most people are diagnosed between 20 and 40 years old – it places unique challenges on health and social care systems. People with MS ought to be able to study, work, have families and travel the world as they wish. However, the current provision of care does not tend to facilitate such ambitions.

There is no 'gold standard' of MS care, as it must always be adapted to each person's unpredictable and changing healthcare needs. Optimal care is multifaceted, requiring regular interdisciplinary input with proactive and person-centred approaches. Despite improvements and innovation in recent years, people with MS face staggering variations in access to disease-modifying therapies, symptomatic treatments, rehabilitation and practical and emotional support.

We must ensure that every person with MS in Europe has their needs met for timely diagnosis and personalised treatment, interdisciplinary and coordinated care, and adaptable support in daily life.

To achieve this, we need to seamlessly blend healthcare, social care and rehabilitation in a way that truly meets each individual's unique set of needs, goals and circumstances. We must better understand how the condition affects people and their families on a day-to-day basis, and respond with support in kind. We should consider how to personalise care and facilitate greater collaboration between the person with MS and their interdisciplinary team.

RETHINKING MS in Europe provides insights into these common unmet needs and challenges, and clarifies why we need to rethink MS to provide optimal care. It presents the ambition and rationale across Europe, which is subsequently distilled into national-level priorities in the RETHINKING MS country briefs and operationalised in the RETHINKING MS policy assessment tool.

With this project, we are calling for all policymakers, decision-makers, members of the interdisciplinary MS team and patient advocates to come together and reassess how care can be better organised – to benefit people with MS, the health and social care systems, and society as a whole.

'We need to seamlessly blend healthcare, social care and rehabilitation in a way that truly meets each individual's unique set of needs, goals and circumstances.'

People are living with MS for longer than ever before, thus it is essential that we organise services not only to treat needs as they exist currently, but also to prepare for future requirements and challenges. The nature of MS and other chronic neurological conditions demands that we restructure current care models. We hope that RETHINKING MS can act as a catalyst in health policy discussions and planning, helping to reshape health and social systems for the increasing burden of chronic disease and greater care needs of this century.

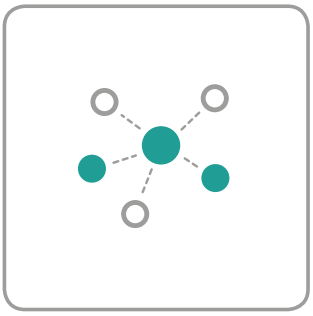
Professor Monica Di Luca,
President, European Brain Council

CALL TO ACTION

We call on policymakers and decision-makers across Europe to develop and implement national strategies for MS that enable:

Timely diagnosis and personalised treatment

Interdisciplinary and coordinated care



Adaptable support in daily life

The following organisations endorse the RETHINKING MS project, including the call to action and policy recommendations, to help improve the quality of life and care for people living with MS in Europe.

EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

emsp
EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

ms international federation

RIMS REHABILITATION IN MULTIPLE SCLEROSIS
European network for best practice and research

ean
the home of neurology

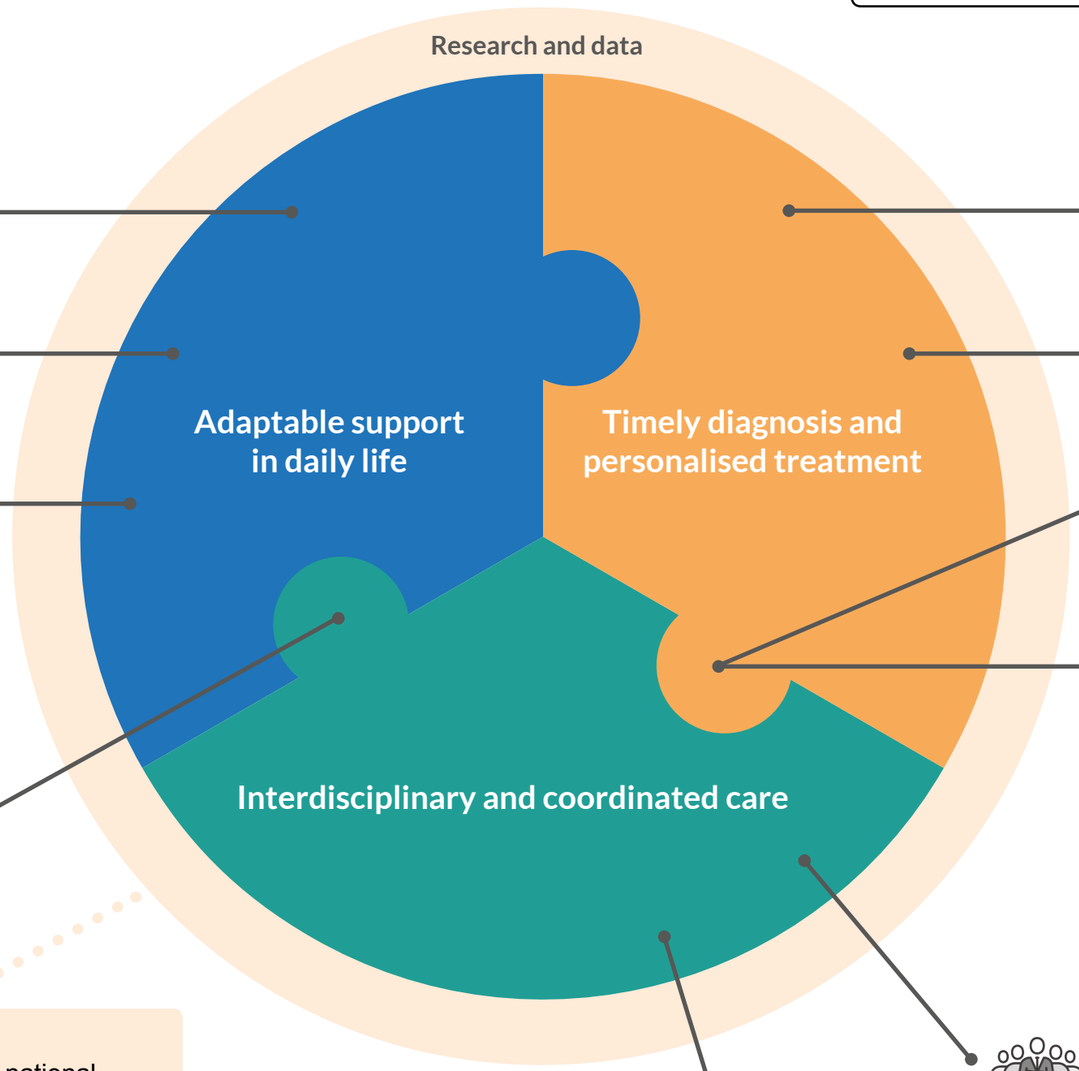
European
Charcot
Foundation

POLICY RECOMMENDATIONS

RETHINKING MS policy priorities

Legend

- Policymakers and government officials
- Research community
- Interdisciplinary teams
- Patient advocacy groups



Ensure consistent resourcing for long-term social care

Revise disability assessments to recognise the complexity of MS

Incentivise and support employers to make workplace adaptations

Integrate health and social care across all MS services

Develop comprehensive national MS registries to collect data on the quality of care and patient-reported outcomes

Invest in research to better understand MS, with a focus on progressive forms

Remove barriers to access and availability of the full spectrum of MS therapies

Co-develop MS care plans between the person with MS and the interdisciplinary team

Fund and support training for MS specialist roles and neurorehabilitation

Expand capacity at MS clinics for regular monitoring of all people with MS

Support people with MS to adopt a brain-healthy lifestyle

Develop comprehensive educational materials for people with MS

EXECUTIVE SUMMARY

Multiple sclerosis (MS) is a chronic condition affecting over 750,000 people across Europe.[1 2] Most people are diagnosed between the ages of 20 and 40,[3] and must learn to live with the disease's unpredictable, variable and often 'invisible' symptoms. The disease is costly to individuals and society: averaging between €22,800–€57,500 per person per year in health and social care costs and lost productivity.[4] As disease severity increases, so do costs associated with MS. There is no cure, so management focuses on: timely diagnosis; slowing the development of disability with disease-modifying therapies (DMTs); therapies to reduce the impact of symptoms; and rehabilitation to support physical and emotional wellbeing. The needs of people with MS in Europe are complex, but may be summarised in three broad themes:

1. Timely diagnosis and personalised treatment

A timely diagnosis is essential to enable a prompt initiation of DMTs and symptomatic treatment which, in turn, can prevent potentially irreversible disability.[5-8] Care must be individualised to each person and their specific symptoms and needs, and often people must try several options before they find an acceptable treatment.[5] Regular monitoring is a key way to personalise care and provide adequate support, and should be received by all people with MS regardless of their treatment regimen.

However, there are often delays to diagnosis and limitations to treatment personalisation.[4 9] Delays can be driven by low MS awareness among the general public and some healthcare professionals, and inadequate access to diagnostic facilities and MS specialists.[10-15] Access to DMTs and symptomatic therapies can also be extremely challenging.[16 17] These issues are compounded by capacity challenges in MS clinics with regard to regular monitoring and effective shared decision-making.

2. Interdisciplinary and coordinated care

Monitoring and management of MS requires a specialist neurologist to draw on expertise from a range of disciplines.[17-19] This interdisciplinary approach – where care is provided by a diverse group of specialists in a collaborative manner – is essential for all people with MS.[18 20-22] Optimal disease management also includes aspects of lifestyle modification, as many 'brain-healthy' lifestyle factors may delay progression and relapses.[5 8 23]

Unfortunately, access to specialist MS roles and programmes is frequently suboptimal and highly variable depending on where someone lives.[21 24 25] Difficulties in providing specialist interdisciplinary services include chronic shortages of MS specialists and challenges in coordination across sectors.[14 26] As a result of this lack of person-centred interdisciplinary care, many people with MS risk 'falling through the gaps' in care.[11 14 15 27]

3. Adaptable support in daily life

Social care can greatly improve quality of life for people with MS, and provide essential support to carers and family members.[22 28] Social workers and occupational therapists can also support people with MS in their professional and daily lives.[29 30] Due to the unpredictable nature of MS, this personalised rehabilitation and social support must be initiated and adapted promptly.

At present, availability and funding of formalised social care is often limited. Disability and social care assessments frequently underestimate the impact of MS. As a result, many people pay out-of-pocket for much-needed support.[31] In addition, employers are often inadequately supported to adapt to an employee with MS.[12] Workplace adaptations exist to help people with MS remain in work,[32-34] but their usage varies widely and most people with MS are not in full-time work.[4]

We need to rethink how MS is managed in order to adequately provide care and support for all people with MS. European and national policymakers should focus their efforts around these themes, and take specific actions:

1. Fund and train MS specialist roles and neurorehabilitation, remove barriers to accessing the full spectrum of MS therapies, co-develop MS care plans between the person with MS and their interdisciplinary care team, and expand access at MS clinics for regular monitoring of all people with MS.
2. Develop comprehensive educational materials for people with MS, support them to adopt a brain-healthy lifestyle, and integrate health and social care across all MS services.
3. Ensure consistent resourcing for long-term social care, revise disability assessments to recognise the complexity of MS, and support and incentivise employers to make workplace adaptations.

INTRODUCTION

Multiple sclerosis (MS) is a complex and progressive disease of the central nervous system, where the immune system destroys brain, optic nerve and spinal cord tissue.[3 5 6] As a result, people with MS develop irreversible motor-disability and cognitive impairment over time.[6 20 35] MS affects almost every aspect of day-to-day life,[36 37] and its personal and economic impacts grow significantly as the condition progresses and disability worsens.[5 7 38] There is no cure for MS, so management focuses on timely diagnosis, slowing the development of disability with disease-modifying therapies (DMTs), rehabilitation to optimise physical and emotional wellbeing, support for self-management, and therapies to reduce the impact of symptoms.[3 5]

One of the most complex aspects of MS is the variability and unpredictability of symptoms. MS affects every person differently[6 24 31 35 39] and it is extremely difficult to predict when symptoms, including 'invisible' symptoms such as fatigue or pain, may strike; this may hinder a person's ability to work or socialise.[7 9]

MS develops when people are young and can have a devastating impact on their lives. It is typically diagnosed between the ages of 20 and 40[3 31] and occurs two to three times more frequently in women than in men.[1 3 6 24] The young age of onset means that education, career and family life can be hugely affected,[5 16 24] impacting financial security and independence.[5 9 32 37] Low workforce participation has wider implications and also affects society more broadly through decreased productivity and a considerable cost to social welfare systems.[4 7 9 40]

Due to its complexity, MS requires a concerted, comprehensive policy response to ensure individuals' health and social needs are met, from diagnosis all the way through their lives. This also requires a collaborative and integrated approach to care. This was one of the key conclusions of the 2017 Value of Treatment report – developed by the European Brain Council and a multidisciplinary expert group – which identified areas for urgent action to reduce the personal, societal and healthcare burden of brain disorders, and specifically MS, across the European Union.[41] Needs for therapies, medical devices, and adequate health and social care services are high and continue to grow. However, for too many people with MS, such needs are not adequately met by existing care and service provision.

Building on this framework, this report aims to take a broad health and societal perspective on how we can develop better policy responses to MS. We need to rethink how we organise and provide MS care to ensure people's needs for therapies, medical devices and appropriate health and social services are met consistently across their lives.

This report – *RETHINKING MS in Europe* – is focused on three key areas which have been identified as priorities for policy action by our interdisciplinary group of experts to meet the needs of people living with MS:

- Timely diagnosis and personalised treatment
- Interdisciplinary and coordinated care
- Adaptable support in daily life.

The report forms the foundation of the RETHINKING MS project, which also comprises country profiles for for Denmark, Italy, Romania and Spain, and a policy assessment tool focusing on these four countries. To find out more about the project, please visit www.braincouncil.eu/RethinkingMS.

What do we mean by integrated care?

Integrating health and social care is critical when rethinking MS. For the purposes of this project, we define integrated MS care as:

A proactive, person-centred approach to health and social care that is highly tailored to the needs, preferences and goals of the person with MS and their family. It should inform people with MS and empower them to participate in decisions about how their care is organised and delivered. It must be coordinated across an interdisciplinary team whose members are able to effectively communicate and share information.

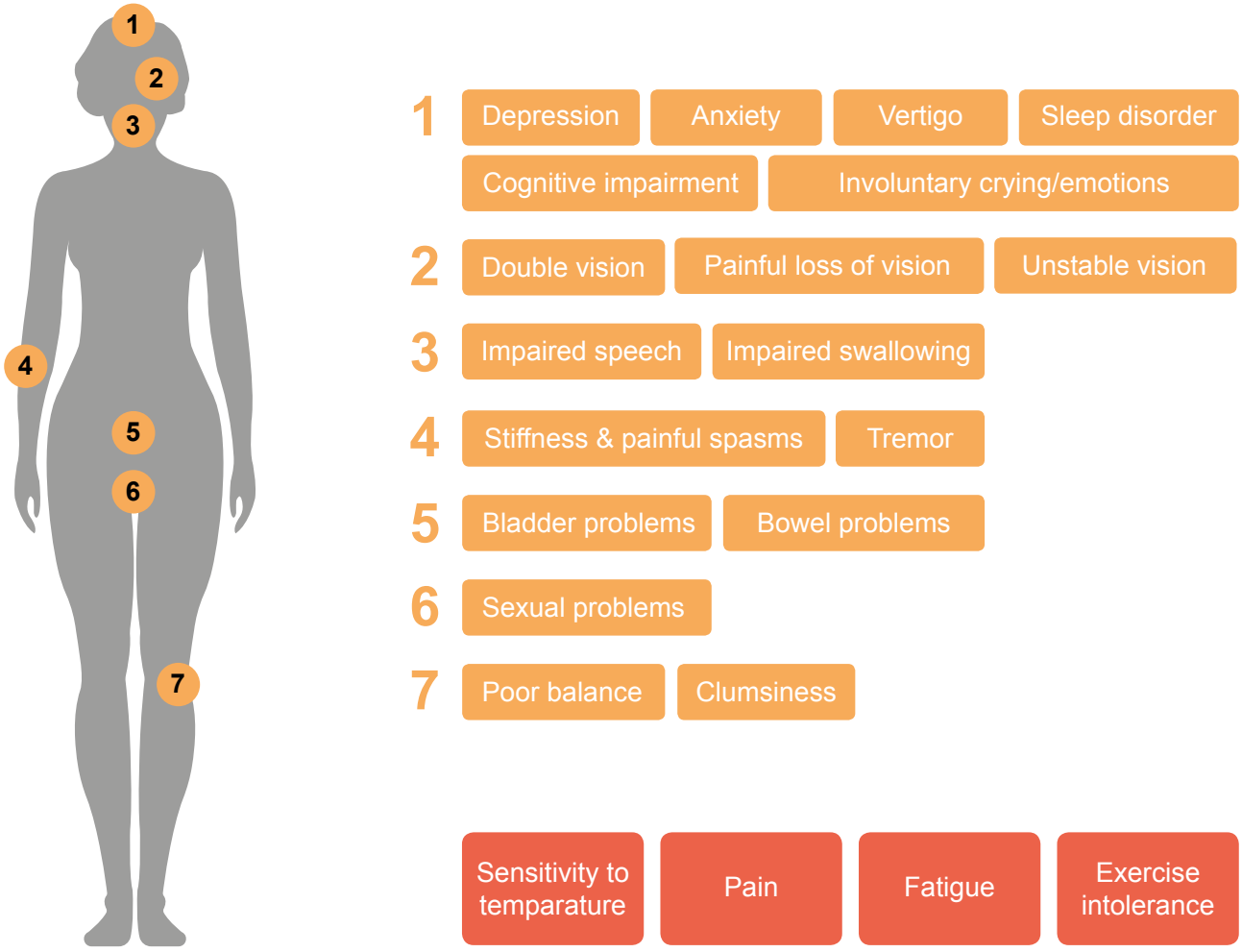
MS: DEFINING THE CHALLENGE

Symptoms and causes

MS is a chronic neuro-inflammatory and degenerative disease that we still do not fully understand

The underlying causes are unknown, but MS is thought to be caused by complex interactions between genetic and environmental factors.[16 23 42] MS symptoms are heterogeneous and depend on the area of the central nervous system that is affected by the damaging lesions which characterise the disease (*Figure 1*).[5 9 16 17] Symptoms may change over the course of the disease.

Figure 1. Common MS symptoms



Adapted from Giovannoni *et al.* 2017[5]

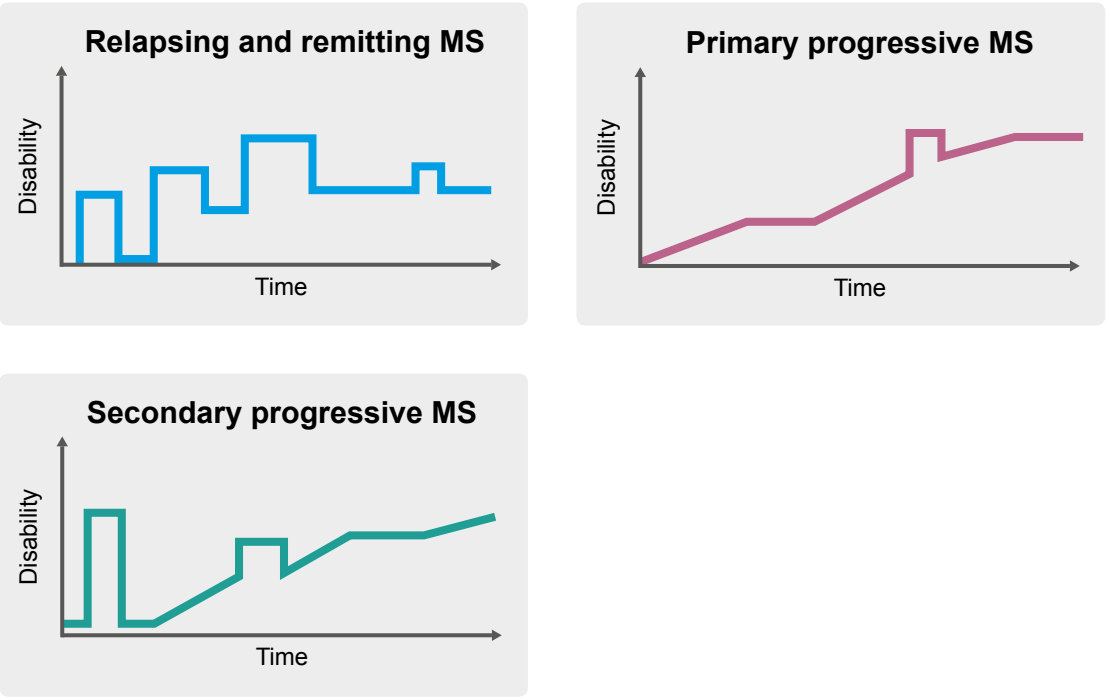
Classification

There are four main types of MS:

- **Clinically isolated syndrome** (CIS) is the first clinical presentation of inflammation or lesions.[43] However, many people with CIS will not go on to develop MS.[44] If CIS becomes clinically active and fulfils the current diagnostic criteria, it can be reclassified as relapsing and remitting MS.[43]
- **Relapsing and remitting MS** (RRMS) is characterised by intermittent 'relapses' (sudden onset of MS symptoms and disability), followed by remission periods where symptoms abate.[9 16] Approximately 85–90% of people with MS have RRMS at diagnosis.[3 9]
- **Secondary progressive MS** (SPMS) is characterised by progressive accumulation of disability after an initial relapsing course. There are no clear criteria to mark the transition between RRMS and SPMS, and often SPMS is only diagnosed retrospectively.[43]
- **Primary progressive MS** (PPMS) is where disability accumulates without relapses from the outset.[43]

These types are defined by the pattern of progression and relapses over the disease course (*Figure 2*).

Figure 2. Disease course for MS



Adapted from MS Society,[45] based on Lublin 2014[43]

In addition, all types of MS can be further classified to provide information to guide therapeutic decisions:[43]

- **Active/not active** – evidence of new neurological symptoms and inflammation based on clinical assessment and brain imaging.
- **Progressing/not progressing** – a confirmed increase in disability over time that is independent of relapses.

Facts and figures

MS is a chronic condition people live with from an early age; most people are diagnosed between the ages of 20 and 40.[3]

MS is the leading cause of non-traumatic neurological disability in young and middle-aged people in developed countries.[24 46]

MS is thought to affect over 750,000 people in Europe.[1 2] While there is considerable variation globally, prevalence and incidence rates in Europe are among the highest.[1]

MS has an ongoing impact on daily life:

- Up to 58% of people with MS are not in employment.[4]
- Carers and families often experience a high financial burden and loss of personal productivity.[7 9]

MS can be expensive to manage:

- The annual cost of MS in Europe was €14.6 billion in 2010, including both direct and indirect costs.[47]
- Average costs of MS can range between €22,800–€57,500 per person per year in Europe (2015), including direct and indirect costs.[4]
- Social care and support needs rise as disability worsens.[5]

Challenges in clinical management

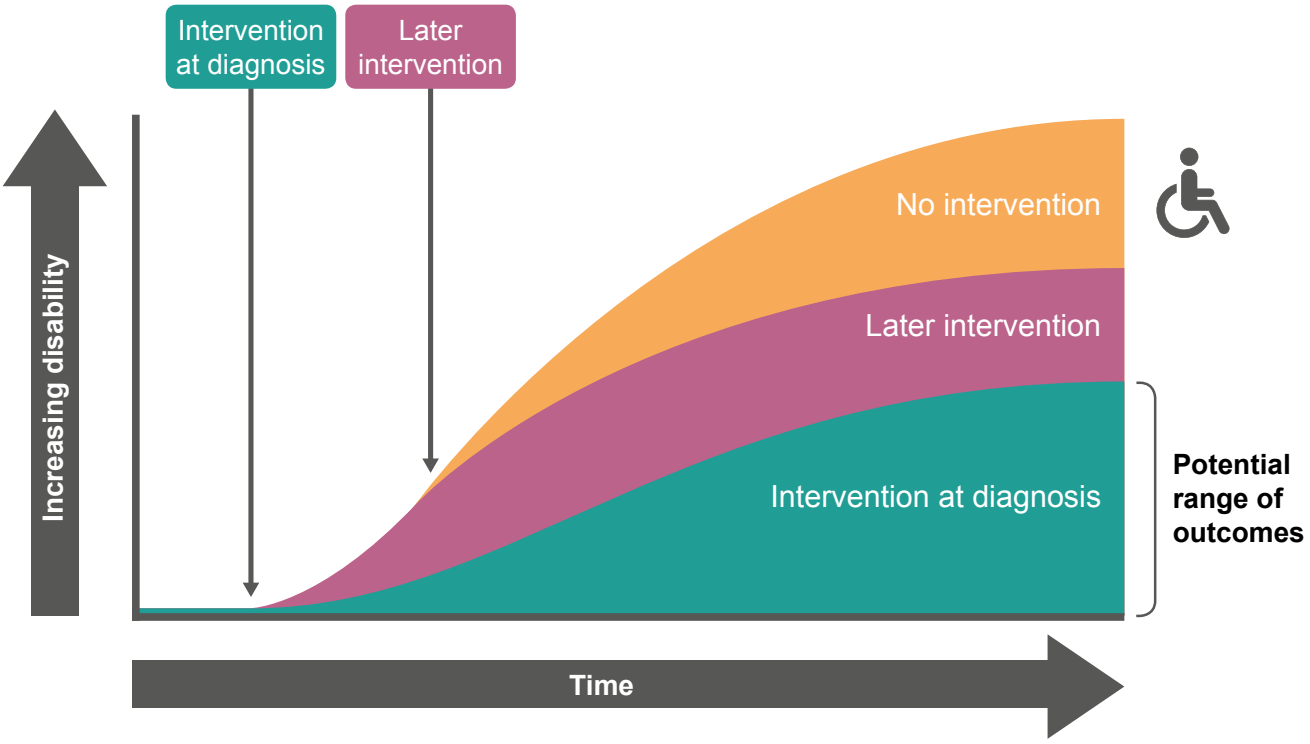
'We are dealing with a disease that has a thousand faces. The challenge is to make sure that every person with MS has the right treatment and support at the right time, at every stage of their life.'

Pedro Carrascal, European Multiple Sclerosis Platform and Multiple Sclerosis Spain

Delays to diagnosis and treatment can cause irreversible worsening of disease and disability

Early diagnosis and initiation of treatment is essential. It can help reduce potential disability and maintain cognitive and physical function, thereby supporting people to stay in work and reducing the negative societal impact.[5 7 48 49] Across Europe, however, many people with MS face delays to diagnosis and initiation of treatment, or do not have access to all treatment options.[5 50] This risks preventable accumulation of neurological damage and worsening of disability (*Figure 3*).[5-7 9 40 50]

Figure 3. The impact of early diagnosis and intervention on MS disability



Reproduced and adapted from 'Brain health: time matters in multiple sclerosis', Giovannoni G *et al*. *Mult Scler Relat Disord* 2016;9 Suppl 1:S5–S48,[5] with permission from Oxford Health Policy Forum

Access to treatment and specialist care is far from equitable, especially for people with progressive MS

Availability of and access to DMTs can vary significantly, often based on cost and location.[9 31 40 51] A person with MS who does not receive DMTs risks 'falling through the gaps' in care.[11 14 15 27 52 53] Despite experiencing a higher burden of symptoms, quicker worsening of disability and greater support needs, such people are usually seen by a neurologist less than once a year.[11 52]

As the World Health Organization has rejected an application to put three MS therapies on the Essential Medicines List,[54] these challenges of access are likely to continue.

The personal burden of MS is often underestimated

Progression or severity of MS is measured to assess health and social needs, and the Expanded Disability Status Scale (EDSS) is frequently used.[55] However, this scale does not fully consider the unpredictable, variable and often invisible symptoms of MS.[5 9 51 56] When disability is not adequately assessed, people with MS are unable to access much-needed care and support.

Rehabilitation helps people adapt to life with MS, but is underutilised

Rehabilitation is an essential component of MS care, incorporating highly personalised education, physiotherapy, cognitive retraining, fatigue management and other interventions based on the needs of each person with MS. However, it is too often underutilised as an opportunity to prevent or delay disease progression and help people maintain family, social and working lives.[25 57]

Data challenges

'Building a robust disease registry must be a top priority for any country looking to address MS. We cannot understand what we cannot see.'

Professor Melinda Magyari, Danish Multiple Sclerosis Center

MS is inherently difficult to study and fundamental data are inadequate

The unpredictable, diverse symptoms across a progressive condition can make conducting research on MS challenging. Even data on the number of people living with MS in Europe are limited and out of date, with estimates ranging from 609,000 to 740,000.[40 58 59] As incidence has been rising steadily in recent years, experts suggest that over one million people in Europe now live with MS.[52]

Despite multiple benefits, few European countries have comprehensive MS registries

Just 15 European countries have national MS registries, though some countries provide data to voluntary international registries or have smaller databases (*Box 1*).[58 60 61] However, registries often collect different types of data, preventing robust cross-border analyses.[61]

Establishing disease registries is the first step towards fully understanding the burden of MS. They can support benchmarking, understanding of variations in performance and patient-reported outcomes, evaluation of national strategies and identification of best practice.[62-65]

Box 1. Examples of MS registries

The European MS Data Alliance (MSDA)[66 67] is a project from the European MS Platform (EMSP) and the University of Hasselt to implement core data measures and quality standards into existing MS data registries and cohorts. Wider adoption of these protocols will lead to data which can be pooled and compared for greater analytical power and understanding.

The Danish Multiple Sclerosis Registry[68 69] is a comprehensive national registry established in 1956, which collects information on all Danish residents diagnosed with MS. Personal identification numbers allow cross-referencing with other national registries and databases.

Szegedi Sclerosis Multiplex Regiszter[70-72] is a local registry in central Hungary, which grew from a simple demographic disease study to a more advanced registry.

MS: ADDRESSING THE CHALLENGE

'MS places a huge burden on the person with MS, their family, and health and social care systems. The impact can be significant. This calls for a comprehensive policy response to MS in our societies.'

Professor Jenny Freeman, University of Plymouth, UK; representative of Rehabilitation in Multiple Sclerosis (RIMS)

Uncertainty over MS prevalence makes developing adequate health and social care policies extremely difficult. The complexity of MS further challenges the provision of health and social care, resulting in highly variable access to specialised care and support across Europe.

The following sections will look at these unmet care needs across:

- timely diagnosis and personalised treatment
- interdisciplinary and coordinated care
- adaptable support in daily life.

Each section will explore how these areas affect people with MS across Europe, including the existing gaps and potential solutions to adequately address the challenge of MS.

Timely diagnosis and personalised treatment

What do we need?

- Easy access to MS specialists to facilitate a timely diagnosis after symptom onset
- Treatment that is rapidly initiated, escalated and/or switched when necessary
- Care that is personalised to the specific needs and goals of each person with MS
- Regular monitoring and assessment of progression and disease activity for all people with MS

What is important?

'We must deliver a timely diagnosis and quick initiation of MS treatment. To do this, we need better awareness of the condition, particularly in the early stages.'

Iza Czarnecka, NeuroPositive Foundation, Poland

Optimal MS care depends on timely diagnosis

Timely diagnosis is essential for prompt initiation of DMTs and symptomatic treatment[5-8] – which, in turn, is needed to prevent potentially irreversible disability.[5 7] MS can be a complicated condition to diagnose[73] and many different conditions are often mistaken for MS.[6 39] A person with suspected MS should, therefore, receive rapid referral to a neurologist, ideally an MS specialist.[5 6] Experts recommend that people who report symptoms potentially related to MS should be referred to a neurologist within 10 days, and that accurate diagnosis of MS should be made within four weeks of referral.[8]

MS care must be individualised to each person and their specific symptoms and needs

MS can be a challenging condition to manage, due to its unpredictability and people's changing healthcare needs.[24] Management strategies aim to reduce disease activity and development of disability but must be tailored to each person. They typically fall into three categories:

- DMTs
- Symptomatic therapies and rehabilitation
- Lifestyle interventions.

Each of these strategies is described in more detail in *Boxes 2–4*.

Box 2. Disease-modifying therapies

DMTs reduce the relapse rate and accumulation of lesions at the early stages of the disease.[9] There is substantial evidence showing the benefits of early use of DMTs.[5 7 49] A number of DMTs for MS are approved in Europe. However, there are still significant unmet therapeutic needs, especially for progressive forms of MS. New treatments are currently under investigation to address this shortage.

Choosing a DMT

Every person eligible for a DMT must weigh up the risks and benefits of the available options including method of administration, monitoring requirements and side effects.[5 74] The choice will be personal; for example, some people may prefer oral DMTs to injections or infusions.[75 76] Each individual must find their preferred therapeutic option with their healthcare team, because treatment adherence is vital to optimising efficacy and safety.[51 74]

Escalating or switching a DMT

In the case of suboptimal response, disease breakthrough or intolerable side effects, the neurologist should promptly escalate or switch the therapy.[5 7] However, escalating or switching a DMT may place an additional burden on both the person with MS and the healthcare system due to an increased need for planning, monitoring and testing. In particular, if switching DMTs a 'wash out' period may be required, as some overlapping therapies could interact negatively. This time between treatments risks a re-emergence of symptoms and side effects.[77]

Stopping a DMT

Treatment should be started early, and outcomes should be regularly assessed. Therapy should not necessarily be stopped following progression to SPMS.[7] However, after a certain point, the adverse effects associated with DMTs may outweigh the benefits of treatment. A careful balance must be found.

Box 3. Symptomatic therapies and rehabilitation

MS symptoms can hugely affect daily life;[78 79] adequate symptomatic treatment, including rehabilitation, can improve quality of life and independence.[17] People with MS need a rapid diagnosis of their symptoms and timely initiation of treatment coordinated by their interdisciplinary MS team.[17 19] Symptom management should aim to be proactive and incorporate prevention of symptom development rather than simply reactive approaches.[80]

What symptomatic therapies exist?

Pharmacological therapies with a strong evidence base include those for spasticity, trigeminal neuralgia (pain) and bladder dysfunction.[19] Some therapies exist for other common problems, but with limited evidence of effectiveness.[19]

There are non-pharmacological rehabilitation interventions for many MS symptoms, including: physiotherapy or occupational therapy for spasticity, ataxia, fatigue, weakness and functional difficulties;[19] cognitive behavioural therapy for depression;[19] counselling for sexual dysfunction;[81] and memory rehabilitation for cognitive impairments.[82]

Box 4. Lifestyle interventions

Various lifestyle factors have been associated with onset of MS in the general population and progression in people with an existing diagnosis.[38 42 83] Interventions to address these risk factors can slow the worsening of disease in people who already have MS or reduce the impact of comorbidities, and are important for overall health and wellbeing.[23 38 40 84] Lifestyle modifications thus have an important role in reducing the societal and healthcare costs associated with MS:[38]

- Physical activity is associated with fewer comorbidities and better overall health, and has disease-modifying effects.[23 57 85]
- Safe sun exposure or vitamin D supplementation may help prevent disease activity.[86-89]
- Smoking is associated with disease progression and disability.[5 23 42 90] Smokers are more likely to have progressive disease and progress at an earlier age.[90]

Personalised approaches to care are critical to address the diversity of MS

There is no 'gold standard' of treatment in MS[3] and everyone experiences the disease differently.[5] As it is a progressive condition, a personalised, responsive and anticipatory approach must be offered at every stage of illness. It is impossible to be sure who will benefit from a given therapy, and people often need to try several options before they find their optimal treatment.[5] Research into genetic testing and biomarkers may help with this by improving personalisation of treatment, predictability of disease and management of progression. Finding the right therapeutic approach is essential to ensuring treatment adherence and preserving quality of life.

Regular monitoring facilitates tailoring of care and support to the individual

Monitoring – which encompasses safety monitoring for people on DMTs or, at a minimum, annual disease status checks – can help neurologists understand the rate of progression, evaluate the effectiveness of the treatment plan and modify it as necessary.[5] All MS specialists may use regular appointments to encourage adherence to treatments and lifestyle changes, or initiate symptomatic therapies.[8] This can also provide an opportunity for people with MS to ask questions about their care, improve their understanding of the condition, and discuss how their goals and priorities fit with their treatment plan.

What are the gaps?

There are long delays to diagnosis

Across Europe, diagnosis may be stalled by various factors including delays in recognising symptoms, slow referral to specialists, delays in access to magnetic resonance imaging (MRI) scans, outdated guidelines and other issues.[14 26 53 91-94] It is challenging to accurately quantify this problem as symptom onset can be difficult to identify. However, surveys have reported delays of several years between reported symptom onset and diagnosis.[4 9]

MS awareness among the general public and some healthcare professionals is low

People may not connect their varied symptoms with a serious condition such as MS,[10 95] meaning that they often present to different points in the healthcare system, such as primary care, physiotherapists or opticians.[6 91] Non-MS-specialist healthcare professionals may not be aware of the subtle symptoms of MS, delaying referrals and diagnosis.[10-14 94]

Access to diagnostic facilities and MS specialists is often inadequate

Variations in access to specialists and diagnostic facilities may drive regional or national variations in time to diagnosis:

- Limited access to specialist MS healthcare professionals remains an issue in many parts of Europe.[12 31 52 53 91 94 96]
- Limited access and long waiting times for MRI machines inhibit a timely diagnosis.[5 92 94] For example, Germany has 34.5 MRI machines per one million population, while Poland has just 7.9.[97]

Case study 1:
Interactive map showing availability and waiting times for specialist services[98 99]

The Polish MS Society has developed an interactive map of MS treatment clinics, which enables people to sort centres by services, treatment types, waiting times and specialisation. Waiting times for MS treatment can be significant in Poland, and the map allows people with MS to directly provide feedback and information on their experiences. This is expected to lead to improved transparency, accountability and record-keeping at Poland's MS clinics.

There is limited and inconsistent access to DMTs across Europe

Some people with MS wait for years after diagnosis to receive DMTs, despite being eligible.[7 53] This may be due to delays at the national or regional level for approval and reimbursement, alongside cost containment measures such as waiting times. The price of DMTs may also inhibit access, particularly in low- or middle-income countries.[7 24 40]

Institutional and regulatory barriers affect access to DMTs

Choosing and initiating treatment with DMTs is subject to approval and reimbursement issues and prescribing guidelines.[5 31 51] For example, due to cost containment measures in Denmark, the vast majority of people with MS eligible for DMTs are started on the same oral DMT,[11 52] whether it is appropriate or not.

Neurologists sometimes face external pressures and limitations on the number of people for whom they can prescribe DMTs.[31] Cost containment pressures are particularly prevalent in Eastern European countries.[12 96]

Access to symptomatic therapies is limited

Not all MS symptoms have an effective therapy;[16 17] for example, there are many treatments available for spasticity and depression, but treatments for sexual, bowel and cognitive dysfunction, as well as fatigue, are limited.[27 52 78] Many symptomatic therapies are not licensed specifically for people with MS, which may pose challenges to access.[17 19] In addition, not all symptomatic treatments are readily accessible. For example:

- A European survey showed highly variable use of symptomatic therapies in MS, ranging from 22.4% in Denmark to 34.4% in Spain and 53% in Italy.[100-105]
- A nationwide MS registry in Germany reported in 2018 that fatigue was only treated in one third of affected people, despite treatments being available.[78]

Regular monitoring is essential but inconsistent and under-resourced

For a person on DMTs, safety monitoring typically occurs every three or six months. In many cases, the specialist neurologist must carry out such assessments, and this frequency can be a challenge to clinic resources and capacity. Safety monitoring can also place a burden on people with MS who may need to travel long distances for appointments.

As safety monitoring is linked to use of DMTs, most people with PPMS and SPMS may not be monitored regularly because this treatment is not standard practice in progressive MS. They should still have their disease status monitored – but many do not even have annual appointments with neurologists or MS specialists.[15 27 52 75] When a person with RRMS progresses to SPMS, they may continue with DMTs as long as they and their neurologist agree it is beneficial. For others, however, monitoring is prompted only after they report a relapse or progression of disease and symptoms,[50] and there is a lack of standardised care and support between relapses or periods of deteriorating health.[10 15 27 52 94]

Please see the country profiles for Denmark, Italy, Romania and Spain for an in-depth analysis of access to timely diagnosis and use of personalised MS management strategies in these countries.

What can be done?

Fund and support training for MS specialist roles and neurorehabilitation

Remove barriers to access and availability of the full spectrum of MS therapies

Co-develop MS care plans between the person with MS and the interdisciplinary team

Expand capacity at MS clinics for regular monitoring of all people with MS

Interdisciplinary and coordinated care

What do we need?

- Access to specialist-led interdisciplinary care for all people with MS at all stages of their condition
- Education to empower people with MS to participate in shared decision-making
- An emphasis on brain-healthy lifestyles to help slow MS progression from disease onset

What is important?

'As MS is such a complex and variable condition, classic chronic care models that you see in other conditions may not always be appropriate without significant adaptations. Any MS model has to be built around the patient and deeply ingrained in both health and social care systems, rather than built around existing structures.'
Professor Mario Alberto Battaglia, Italian Multiple Sclerosis Association and Italian Foundation for Multiple Sclerosis

People with MS benefit from being engaged and involved in their care

Engaging people with MS in their care decisions is key to successful management.[5 56] Shared discussions help the person with MS to assess therapeutic options in the context of their personal aims and priorities.[5 9] It is also important to involve carers and family members in these discussions, to help them understand and prepare for a future with MS.

People with MS should be given unbiased and accurate information about therapeutic options and the MS disease course tailored to their specific needs, which will facilitate engagement in shared decision-making and ensure a personalised approach.[15 51 74 106] Typically, the MS specialist neurologist or MS specialist nurse is responsible for providing such education.[107]

Information and care should meet the changing needs of the person with MS

Timing, content and frequency of education is hugely important as people may not wish to learn about MS immediately after diagnosis.[73 106] Willingness to engage in care and shared decision-making may have many cultural and personal influences, and will likely change across the disease course.[20 74 75 106] Similarly, the MS care team will also need to evolve and respond to the changing needs of the person living with MS.

Interdisciplinary approaches are essential for all people with MS

Monitoring and management of the diverse MS symptoms and DMT side effects across a lifetime with MS requires the specialist neurologist to draw on expertise from a wide range of disciplines across health and social care (*Box 5*).[17-19] Complex chronic conditions such as MS are unlikely to be optimally managed outside interdisciplinary collaborative care models.[84] MS does not preclude other health challenges: comorbidities also require effective prevention, treatment and specialist input. For the many people living with a dual burden of disease, the need for integrated person-centred care is particularly urgent.

What do we mean by interdisciplinary care?

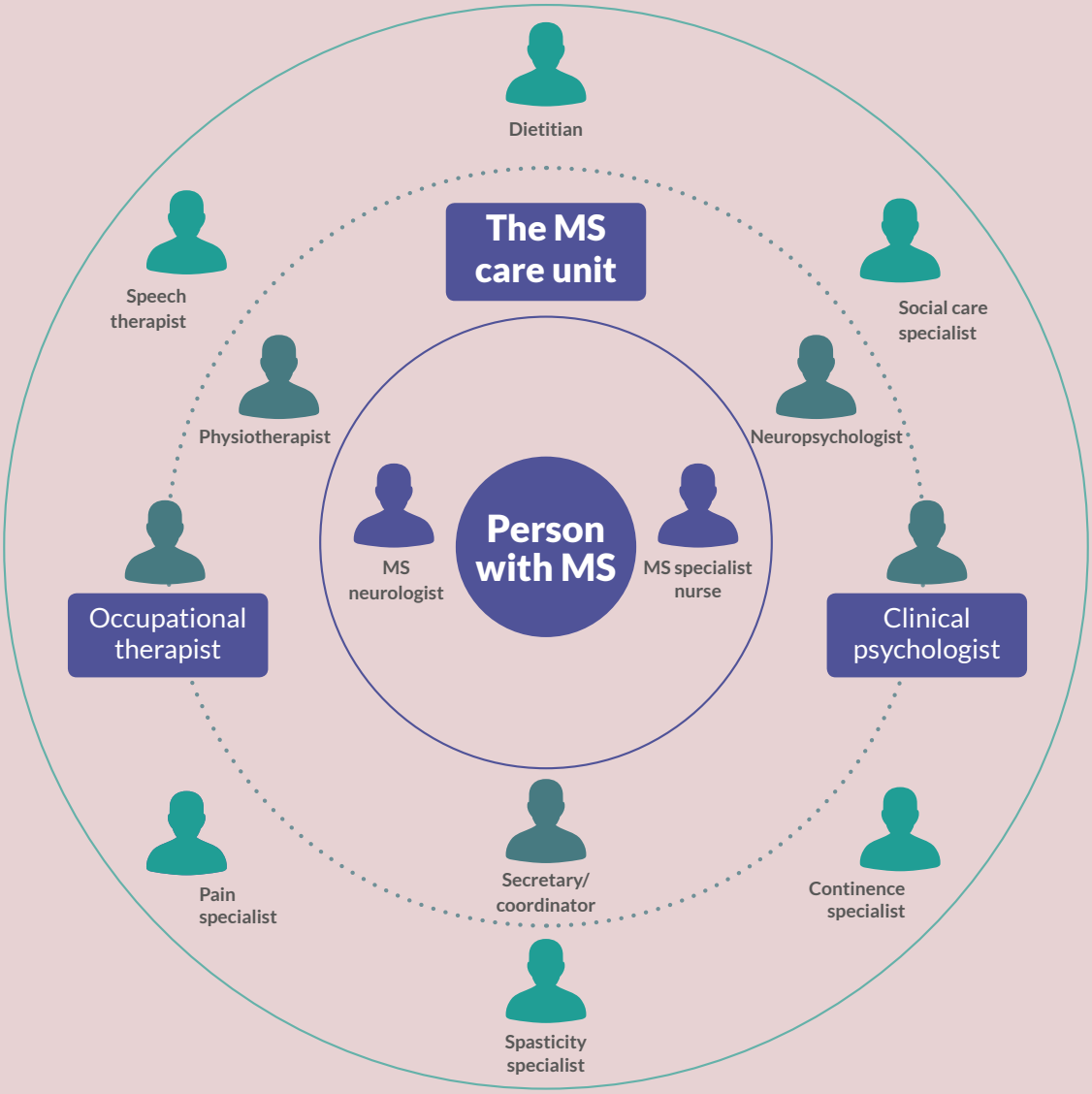
The provision of care from different healthcare professionals can be described in many ways.[108 109] In this report, we use 'interdisciplinary care' and define it as:

A coordinated approach across a diverse range of settings and specialties where care is planned and carried out in a collaborative manner, with shared resources, information, responsibilities and decisions. The patient and their family are central actors in the interdisciplinary team.

Box 5. Who could be part of the interdisciplinary MS team?

Depending on the needs of the person with MS, specialist neurologists should be able to collaborate with a range of other specialists. *Figure 4* shows the organisation of an interdisciplinary MS team spanning health, social care and rehabilitation.

Figure 4. Organisation of an interdisciplinary MS care team



Regular collaborators:

- General practitioner
- Social care/home-care service
- Neuro-radiologist
- Neuro-ophthalmologist
- Neuro-rehabilitation
- Urologist

Occasional collaborators:

- Dermatologist
- Gynaecologist/obstetrician/ midwife
- Internal medicine specialist
- Surgeon
- Orthopaedics
- Neuro-otologist
- Psychiatrist
- Neurosurgeon
- Pain clinic

Adapted from Soelberg Sørensen *et al.* 2018[21]

Case study 2:
An interdisciplinary MS unit providing clinical support and rehabilitation[110-112]

Hakadal, Norway, is home to the country's specialised MS care unit, managed by MS Forbundet (the MS association of Norway). Offering two-week intensive care and three- and four-week rehabilitation stays, it provides care from a wide-ranging interdisciplinary team with a neurologist, nurse, neuropsychologist, occupational therapist, physiotherapist, psychologist, social worker, nutritionist, speech therapist and urologist. People who are interested are referred by GP, MS nurse or neurologist. The unit offers different types of stay, including rehabilitation for work, and courses for newly diagnosed people and relatives or carers of people with MS. A study on patient satisfaction found that more than 85% believed the stay would have a significant positive impact on their quality of life moving forward.

Lifestyle changes can help to prevent relapses and slow progression

Optimal MS management includes aspects of lifestyle modification, as many 'brain-healthy' lifestyle factors may reduce progression and relapses.[5 23] Lifestyle education and interventions should be considered by the healthcare team immediately after diagnosis in order to maximise brain health and slow the accumulation of disability.[5 8] However, maintaining lifestyle changes can be extremely challenging and requires lifelong effort, thus interdisciplinary and personalised support and coaching can be extremely helpful.

Technology can facilitate open communication and integrated care

There is potential for new technologies to improve communication between people with MS and their interdisciplinary team.[113] Clinics are beginning to experiment with telemedicine as a way of managing people living in rural areas.[14] The use of mobile applications as healthcare tools is also expanding, and there are apps to support people with MS with their varied needs including symptom monitoring, self-management, socialising, and tracking therapies and side effects.[114 115] Along with improving daily living, these can be helpful as discussion aids for appointments with the interdisciplinary team.

The efficiencies gained from adopting technological solutions may improve monitoring and responsiveness, allowing more personalised treatment and care.

Case study 3:
An award-winning app supporting clinicians to diagnose and manage MS[113 116 117]

The Multiple Sclerosis Diagnosis and Management App was developed in the US to assist practising neurologists, physicians and other healthcare professionals in diagnosing and managing people with MS. Based on US guidelines, it includes diagnostic criteria, imaging studies, symptom management guides and a dedicated section on mental health. The highly rated app was designed by the US National MS Society and Borm Bruckmeier Publishing and is available worldwide.

Palliative care is a key aspect of support for people with MS and their carers

Palliative care aims to achieve the best possible quality of life for people with MS, focusing on intensive symptom management and carer wellbeing.[118 119] It should complement neurology and rehabilitation services.[119] Palliative care and effective communication can improve care for people with neurodegenerative conditions.[118 120]

What are the gaps?

There is a lack of suitable information for people with MS

Many people with MS and their carers do not feel that they receive suitable information, advice and education from healthcare professionals.[10 73 91 96] For example:

- People with MS have reported that information on DMTs is not always clear.[74]
- Carers in France (60%) and Germany (67%) have reported feeling that healthcare professionals did not describe the disease, progression and care needs well.[121]

Due to capacity and resource issues in many countries, information is often provided by the national MS society or local patient groups rather than healthcare professionals.[53 91 122]

The lack of timely information can cause confusion,[9] stress and anxiety,[73] and impact the person's ability to make decisions about treatment. Many people with MS experience difficulty finding reliable and up-to-date resources.[51] The volume of available information has been described as overwhelming, which can affect motivation for engagement and self-management.[9 51]

People with MS are not always involved in decisions about their care

Shared decision-making is often better in the early stages of RRMS and declines as severity increases.[76] This may be, in part, due to reduced options for DMTs. It is compounded by very short appointments with neurologists – sometimes under 10 minutes – which may restrict opportunities for shared decision-making and education.[11 27 91]

Providing interdisciplinary and coordinated care is organisationally challenging

It can be difficult to provide high-quality interdisciplinary care, particularly in low-resource settings. There is typically a lack of communication between the health and social care systems, meaning many people do not receive the treatment and support they need. Capacity can be a challenge in many MS clinics due to low numbers of specialists, large caseloads and high requirements for DMT monitoring.[12 14 26 91] This may impede interdisciplinary working, and even simply the ability to provide personalised consultations and education to each person with MS. Administration of MS care can sometimes be overseen by administrative or care coordinator roles, but their use is limited,[14 75] and the task of coordinating care falls largely to the person with MS.

Access to specialist MS roles and programmes is limited

In many countries, people with MS are predominantly treated in smaller clinics in the community, resulting in variable access to a full interdisciplinary team.[20] Geographical and financial inequalities can affect access to specialist services and facilities.[13 14 27 91 92] Palliative care and psychological support are particularly challenging to access, and are typically not tailored to the unique MS experience.[14 31 53 73 95] A lack of MS-specialist training programmes for healthcare professionals further hinders access to specialists.[31]

Case study 4:
Free online training to meet the demand for MS specialist nurses[14 123-125]

In an effort to improve the supply and standard of much-needed healthcare professionals, EMSP's NursePRO offers an online course for nurses looking to specialise in MS. Nurses receive internationally recognised accreditation upon completion of all modules, and additional accreditation is offered by the Multiple Sclerosis Nursing International Certification Board. Available in 11 languages, the course has received endorsement from many nursing organisations, MS societies and patient groups. While originally conceived as a European project, the programme's success has sparked expansion and it is now offered in countries across the Americas, Africa and Asia.

Availability of and access to rehabilitation programmes varies widely across Europe

Rehabilitation is underutilised as an opportunity to prevent or delay disease progression.[57] Programmes are often not fully integrated or initiated early enough in MS management plans;[15 57] in some countries, they are entirely separate.[52 91] Across Europe access to occupational therapists, psychosocial care professionals, speech therapists, physiotherapists and psychologists is frequently suboptimal,[10 21 27 91 92] and there are geographical inequalities.[25] As a result, such roles are commonly provided privately or via patient associations.[126]

Lack of expertise contributes to the great variations in access[15 20 24 91] as there are often too few rehabilitation centres specialising in the disease and limited numbers of MS rehabilitation specialists.[91]

Funding for rehabilitation is often suboptimal, meaning that many people are forced to pay out-of-pocket for care, further driving inequalities.[31] Rehabilitation services are more likely to be fully or mostly reimbursed in Western Europe than in countries further east;[25] in Greece and Bulgaria, for example, rehabilitation is typically funded privately.[91 94]

Few large-scale studies have looked into lifestyle improvement initiatives

Despite a wealth of research regarding exercise benefits as part of a brain-healthy lifestyle, there appears to be little translation of the findings into daily practice.[127] However, lifestyle modifications can be extremely difficult to maintain over a lifetime. This may be partly due to limited or inadequately tailored support: for example, a US study found that many people with MS are unsatisfied with exercise promotion provided by their healthcare providers.[128] They want greater provision of information and resources, and behavioural strategies to help maintain their fitness regimens.

Case study 5:
Supporting people with MS to live active lifestyles while providing professional education to the clinical community[129] [130]

MovetoSport is a Flemish non-profit organisation focused on supporting people with MS to lead active lifestyles and promoting wellbeing to both people with MS and healthcare professionals. MovetoSport organises activities and events for people with MS and produces academic research on their effectiveness. It also offers certification to exercise therapists and physiotherapists across Flanders, aiming to improve generalists' knowledge of MS. Its achievements include running a trek to Machu Pichu for nine people with MS who, upon their return, reported increased sense of wellbeing, improved mental health and a better sense of ownership over their bodies.

Please see the country profiles for Denmark, Italy, Romania and Spain for an in-depth analysis of interdisciplinary and coordinated care in these countries.

What can be done?

- Expand capacity at MS clinics for regular monitoring of all people with MS
- Develop comprehensive educational materials for people with MS
- Support people with MS to adopt a brain-healthy lifestyle
- Integrate health and social care across all MS services
- Fund and support training for MS specialist roles and neurorehabilitation

Adaptable support in daily life

What do we need?

- Improved practical and emotional support for people with MS and their families
- A broader assessment of disability in MS that adequately reflects the unpredictability and variability of the condition and its symptoms
- Better use of rehabilitation and assistive adaptations
- Support and flexibility from employers and colleagues to enable people with MS to remain in work

What is important?

'We need to ensure that people with MS have access to rehabilitation (including specialised neurorehabilitation centres, new technology and innovation) and the right support to allow them to maintain their energy reserves, maximise their independence and stay in work.'

Cristina Vlădău, Association of Patients with Neurodegenerative Conditions, Romania

Optimal MS management can enable participation in daily life

As MS begins at a comparatively young age, it can affect relationships, family planning and the ability of the person with MS to provide and care for their family in the way they would have liked. Optimising MS management in a way that is consistent with each person's priorities and goals can help people adapt to life with MS.[32 34] This could involve prioritising physical rehabilitation and fatigue management to enable travel, practical help to continue education, or additional clinical support around family planning. This requires close collaboration between the person with MS and their interdisciplinary team that is adaptable to the changing priorities and goals across a lifetime.

The lives of family members are also impacted by MS

Supporting and caring for someone with MS can take significant energy, time and resources.[29 131] This increases as MS progresses to the more severe stages.[4] Social support can greatly improve engagement in care and quality of life for people with MS, but supporting and caring for someone with MS can place a burden on family members.[29 40 131 132] In some cases, caring responsibilities may significantly affect people's personal or working lives, necessitating changes to schedules or even leading carers to stop working.[30 32 121]

Support needs vary widely and require adaptability

Support is essential to help people with MS and their families adapt to life with MS; however, due to the unpredictable nature of MS it must be initiated or adapted promptly. There are typically three forms:[131]

- **Emotional and psychosocial support** are crucial and can help provide meaning, happiness and new goals for the person with MS and their family in the context of an uncertain future.[133]
- **Information on MS** is essential to engage the person and their family in the decision-making process.
- **Practical support** includes:
  - » social care to help with daily tasks such as dressing, cooking or housework[134]
  - » financial support such as disability pensions, transport allowances and benefits for people with MS and their families.[31]

Case study 6:
Improving support with a global social network for people with MS[135]

Two years after diagnosis, George Pepper co-founded Shift.ms to address the isolation, loneliness and confusion commonly experienced by people with MS. The website allows users to communicate and share information, and provides educational content on MS. In 2018, the site had 305,000 visitors including 25,000 members from across Europe, Australia and the Americas. More than 80% of users reported feeling better informed about MS and their treatment choices, and were able to get the information they needed within 24 hours of posting in the forums.

Case study 7:
Localised support for people recently diagnosed with MS and their carers[136 137]

Getting to Grips with MS is a course offered by the MS Society UK, catering to people newly diagnosed with MS as well as their family, friends and carers. The course is run by local MS Society groups across the country, which adapt the course by bringing in local experts and healthcare professionals. The course has been praised by people with MS for helping them to feel less alone and better informed about managing their condition, and to understand the many ways they can continue to live their lives to the fullest.

Social workers and occupational therapists are needed to support people at home and work

Healthcare professionals may not be adequately equipped to fully support people at home and work, thus social workers and occupational therapists can help people adapt to life with MS.[22 28] Home adjustments or mobility aids can help people maintain independence and energy reserves.[40] A physical or occupational therapist often helps with assessing needs and making recommendations, such as easy-grip handles on cooking utensils or additional handrails on stairs.[138] Occupational therapists can work with people with MS and their employers to discuss how MS may impact work and explore ways to manage or mitigate issues.[28 33 139]

Maintaining employment can be challenging, but brings many benefits beyond a salary

Work – not only paid employment, but unpaid and voluntary roles – can help people gain self-esteem, build meaningful relationships, maintain independence and ultimately improve quality of life.[28 29 32 140] People with MS who are not working usually have worse health outcomes and higher rates of depression,[29] which may intensify any reduction in quality of life.[30]

However, the unpredictable nature of MS can challenge employment,[29 30] and people may fear stigma and discrimination when disclosing their diagnosis to employers (*Box 6*). Optimal management of MS can help people maintain work. Symptoms such as depression, fatigue, mobility and cognitive impairment are a major reason for leaving the workforce;[14 29 32 34 40] prompt initiation of a DMT after diagnosis results in improved retention in the workforce in comparison to delayed initiation.[48]

Box 6. Disclosing a diagnosis of MS is a difficult and personal choice

It is important to recognise that not everyone will feel equipped, able or willing to speak to their employer about their MS; this is a highly personal decision that cannot be underestimated. In many situations, lack of disclosure will impact the adaptations or level of flexibility at work.[33] However, it can be very challenging to talk about a diagnosis of MS, and people may fear stigma or discrimination.[12 27 32 33 91]

Case study 8: Supporting healthcare professionals to discuss work with people with MS[141]

EMSP and The Work Foundation developed *A guide for Health Care Professionals to have Conversations on Work with People with Multiple Sclerosis*. Generalists may not have extensive experience with MS and can benefit from a simple, straightforward manual which highlights work as an important area that healthcare professionals can support.The guide outlines key facts and figures about employment in MS and important discussion topics for people with MS and their healthcare professionals. Based on academic evidence and written with feedback from hundreds of people living with MS, the guide has been endorsed by the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) and Rehabilitation in Multiple Sclerosis (RIMS).

Simple workplace adaptations can help people with MS to remain in work

Workplace adaptations such as flexible hours, predictable workloads and accessible bathrooms can support people with MS to remain in work.[32-34] A focus on retaining staff is beneficial for businesses as it is likely to be more economically sustainable to make workplace adjustments and retain an employee than it is to hire and train someone new.[142]

After a period of sick leave or unemployment, returning to work can be very challenging.[29] It is important that the burden of organising workplace adaptations should not fall solely on the person with MS; employers and managers need to be aware of tools and options at their disposal,[33] and public funding should be made available to support employers to adapt their workplaces.

Case study 9: Work coaches and resources to help people with MS remain in, stop and/or return to work[143-146]

Developed by MS Vereniging (the MS Society of the Netherlands), MS Werkloket (MS at work) provides information for people with MS and their employers or prospective employers. Materials available include explanations of labour laws and disability rights, as well as guidance in managing MS in the workplace. Personal MS work coaches are available free of charge via telephone, email or online forum, while an in-person consultation is reimbursed by health insurance.

What are the gaps?

Care needs increase with disease progression

People with MS have greater needs for care and support as their disease and disability progresses. For example:

- In Ireland, people with severe MS disability require 2.7 times as many hours of care as people with mild disability.[30]
- In Germany, data suggest that 19% of people with mild MS require informal or family care, rising to 60% for moderate and 84% for severe MS-related disability.[101]
- In Poland, data suggest that 34% of people with mild MS require informal or family care, rising to 69% for moderate and 93% for severe MS-related disability.[104]

Family members of people with MS receive little support

There is often limited support available to help people with MS and their families, resulting in many unmet social, financial and practical needs,[91 94 95] with formal support for carers often only available in the later stages of MS.[53 92] Therefore, family members and informal carers must often meet this deficit in care. For example:

- In Poland, 53% of people with MS require help from their family.[104]
- In the UK, 36% of people with MS who need support rely on unpaid care.[134]
- A 2018 survey of carers for people with MS showed that 22% of Italian carers and 30% of UK carers felt unable to keep a job due to caring responsibilities.[121]

The lack of support available for people with MS and their families has led MS societies and patient organisations to try to fill this gap with support and information,[53 91 92 122] but many people with MS are unaware of such services and unmet needs persist.

Essential home adaptations and mobility aids are frequently paid for out-of-pocket

A 2017 report found that 25% of people with MS in Spain,[102] 23% in Denmark[103] and 49% in the UK made investments in equipment and mobility in a year.[105] Reimbursement for such adaptations is highly variable.[31 92 93] For example:

- In Ireland, income ceilings disqualify some people from Housing Adaptation Grants.[147]
- In Italy, of people who installed home adaptations, only 47% received tax breaks or financial contributions to support the alterations.[148]

Potential workplace adaptations exist, but their usage varies

Limited data are available regarding workplace adaptations, but it seems that in many European countries, workplace adaptations are rare and employers are often inadequately supported to adapt to an employee with MS.[12 27 92 94 122 126] Of the few studies that exist, one in the Netherlands found that 70% of people with MS in work make adaptations, including alterations to work hours (50%) and cognitive aids (36%).[140] The lack of economic evaluations which could support a 'business case' for their use is a barrier to the implementation of workplace adaptations.

Many people with MS are not in employment

At a global level, approximately half of people with MS are not in employment three years after diagnosis, rising to 70% after 10 years.[32] Across Europe, similar trends are seen:

- In Poland, 32% of people with MS do not work due to their condition;[104] this proportion is 33% in France[149] and 52% in Denmark.[103]
- In Ireland, 55% of people with SPMS, 36% of people with PPMS and 19% of people with RRMS do not work due to their condition.[30]
- In the UK, 58% of people with MS do not work and, of those working, 58% work part-time.[32]

Even at low levels of disability, employment rates for people with MS are lower than in the general population.[5 29 32]

Please see the country profiles for Denmark, Italy, Romania and Spain for an in-depth analysis of policies and support in these countries.

What can be done?

- Integrate health and social care across all MS services
- Ensure consistent resourcing for long-term social care
- Revise disability assessments to recognise the complexity of MS
- Incentivise and support employers to make workplace adaptations

CONCLUSIONS

'Management of people with MS should involve professionals who can best meet the needs of the individual and who have expertise in managing the condition. The Charcot Foundation, supported by the European MS Platform, has an initiative to establish interdisciplinary MS care units across Europe, to implement this model of care.'

Professor Per Soelberg Sørensen, Danish Multiple Sclerosis Center

A diagnosis of MS is life-changing, with far-reaching impacts. As a chronic neurodegenerative condition, it affects almost every aspect of life for the person with MS and their family. No two people with MS will have the same experience, and each individual will face a lifetime of learning to adapt to the varying manifestations and challenges of the condition. The health and social care systems must therefore be well integrated and proactive, delivering for each person's unique needs.

The complex nature of MS puts significant pressures on European health and social care systems. This burden can be reduced, however, with early initiation of therapies, rehabilitation and adaptable support. By intervening sooner, health and social care systems can help to slow deterioration of symptoms and preserve quality of life. When people with MS are well-supported, they are free to live their lives with a focus on their families, their ambitions and their aspirations. Without adequate support, they face potentially preventable but irreversible disability and are almost certain to experience significant psychological and economic stress.

The burden of MS across Europe is increasing, and healthcare systems must adapt. Prevalence is rising steadily and, as the MS population grows and ages, we need health and social care systems that are prepared for this future. Coordination between these systems is currently limited, leaving too many people with MS and their families without the care and support they need. Integration across social care and primary, secondary and tertiary healthcare must be strengthened so that people have appropriate support at all stages of their life with MS. To make these changes, we need to rethink how we organise care, making a fundamental shift away from acute care towards long-term, community-based care.

RETHINKING MS hopes to drive meaningful discussions on how to improve MS care across Europe by highlighting three priority areas: timely diagnosis and personalised treatment; interdisciplinary and coordinated care; and adaptable support in daily life. These interconnected challenges represent essential components of optimal and integrated MS care. While differences exist across Europe in how health and social care is organised and funded, the challenges and goals are more similar than might be expected. Commonalities can also be seen between the needs of people with MS and other people living with complex chronic conditions. This is particularly true of other neurodegenerative conditions – further emphasising the importance and urgency of rethinking models of care.

Underpinning each of these challenges – and their potential solutions – are research and data. Without a better understanding of MS treatment, care and the patient experience, failings in care will continue to grow. Decision-makers must have adequate information to support their uptake of the important and ambitious policies necessary to meet the needs of people and families affected by MS.

Finding solutions is not the responsibility of one group alone. It requires close collaboration between policymakers and government officials, interdisciplinary teams, patient advocacy groups and the research community. Without concerted leadership at all levels, the national and international inequalities in MS care will expand and the burden that MS places on society will continue to grow unchallenged. If allowed to happen, this failing will have devastating repercussions on both personal and societal levels.

Providing integrated care is complex and challenging, but essential. Integration between health and social care systems is fundamental in the drive to provide high-quality care not only for MS, but for all neurodegenerative disorders and chronic conditions. Yet, as these systems are often funded separately, integration is rarely given the required attention and political commitment. In light of the growing burden of chronic conditions, and considering the pressures on public resources across Europe, it is vital to improve the efficiency and sustainability of health and social care systems.

We must rethink how we provide MS care. European and national policymakers should enshrine integrated care into formal policy and processes in all European countries. In taking a whole-system approach to meeting the needs of people with this complex chronic condition, they will also be driving a larger change in the structure and delivery of health and social care fit for the 21st century. If we can rethink MS, we will transform our health and social care to the benefit of all.

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About RETHINKING MS

RETHINKING MS is a research-driven project offering tangible policy changes to improve the lives of people living with MS across Europe, building on the 2017 Value of Treatment report from the European Brain Council. In addition to this report, the RETHINKING MS project includes a series of reports providing an in-depth analysis of policy, care and support available for people with MS in Denmark, Italy, Romania and Spain.

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About the European Brain Council

The European Brain Council (EBC) is a non-profit organisation that aims to improve the lives of those living with brain disorders by advancing the understanding of the healthy and diseased brain through bringing together science and society.

About The Health Policy Partnership

The Health Policy Partnership (HPP) is an independent research consultancy, working with partners across the health spectrum to drive the policy and system changes that will improve people's health.

For more information on RETHINKING MS, please visit:
www.braincouncil.eu/RethinkingMS

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EBC
European Brain Council

Rue d'Egmont, 11
BE-1000 Brussels
Belgium
Tel: + 32 (0) 2 513 27 57
info@braincouncil.eu

@EU_Brain
www.braincouncil.eu

The
Health Policy
Partnership
[research, people, action]

68–69 St Martin's Lane
London WC2N 4JS
United Kingdom
Tel: + 44 (0) 20 3857 3643
info@hpolicy.com

@HealthPolicyPtp
www.healthpolicypartnership.com