

# RETHINKINGMS IN SPAIN

A policy brief



# ACKNOWLEDGEMENTS

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## **About RETHINKING MS**

RETHINKING MS is a research-driven project which offers 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. The RETHINKING MS series includes RETHINKING MS in Europe – a policy report providing an analysis of unmet MS care and support needs across Europe, and practical and sustainable policy recommendations – and 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](http://www.braincouncil.eu/RethinkingMS)**



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**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<sup>1-3</sup>

## What is happening in Spain?

There are approximately 47,000 people with MS in Spain <sup>4 5</sup>
Prevalence of MS ranges from 90–125 per 100,000 <sup>6 7</sup>
Average age at diagnosis is around 32–33 years <sup>8 9</sup>
Approximately 70% of the MS population are women <sup>9</sup>

## What are the costs of MS in Spain?<sup>7\*</sup>

	Mild	Moderate	Severe
Direct costs for healthcare (€)	15,360	21,916	24,344
Direct costs for services and informal care (€)	1,250	9,633	27,725
Indirect costs for short- and long-term absence from work and early retirement (€)	3,997	16,901	16,645
Combined direct and indirect costs (€)	20,600	48,500	68,700

\*Average costs per person, per year. Data were collected in 2015. Combined costs are rounded to the nearest €100. The Expanded Disability Status Scale (EDSS) classes MS severity with a score of 0–9: a score of 0–3 is mild, 4–6.5 is moderate and 7–9 is severe. For information on the different types of MS, see the appendix.

# WHAT IS MISSING FROM MS CARE IN SPAIN?

To better understand unmet needs in Spain, interviews were conducted with experts in MS and an interdisciplinary round table was organised. In order to improve MS care, experts recommended that Spanish policymakers and decision-makers should look to ensure:

- timely and equal access to disease-modifying therapies (DMTs) regardless of location
- that all people with MS have access to interdisciplinary care, specialised rehabilitation and psychological support
- disability assessments accurately reflect MS and enable sufficient social care for people with MS and their families.





# COUNTRY CONTEXT

**Despite the impact of recent economic crises on health, social and employment policies, healthcare in Spain has seen some improvements in the past decade.**

Reductions in healthcare spending have led to restrictions to benefits packages and implementation of co-payments for certain medicines and ancillary services.<sup>10</sup> Health system access remains high, however, and overall health status has been improving.<sup>11</sup> Healthcare is considered to be generally well integrated and recent initiatives have focused on improving care for people with chronic conditions and comorbidities.<sup>11</sup>

**Public funding means that access to healthcare is generally good.** Overall health expenditure in 2018 was 8.9% of national GDP, comparable to the Organisation for Economic Co-operation and Development (OECD) average of 8.8%.<sup>12</sup> Most health services are free at the point of use. However, out-of-pocket payments represent 24% of health expenditure in Spain,<sup>10 11</sup> mostly driven by fees for private health insurance. Outpatient prescriptions have a fixed maximum monthly payment depending on household income and other needs-based exemptions.<sup>11</sup>

**Spain's decentralised healthcare system contributes to substantial regional variations in care.** Healthcare funding and governance is shared between the Central Government and each of the 17 Autonomous Communities (ACs).<sup>11</sup> The Spanish Ministry of Health is responsible for authorising all pharmaceuticals, and sets reimbursement for most. It also sets the reimbursement for healthcare services, but provision of care and public health is decentralised to the ACs. Variations exist in priorities and health spending across the ACs,<sup>11 13</sup> leading to differences in the availability of benefits.<sup>10 14</sup> A system of 'compensation funds' aims to reduce unequal financing across ACs, but variations persist.<sup>11</sup>

**A strong primary care system is a key contributor to the cost-effectiveness of Spanish healthcare overall.**<sup>11 15</sup> Primary care centres are organised into interdisciplinary teams that include general practitioners (GPs), paediatricians, nurses, social workers, physiotherapists and other healthcare providers, with the aim of improving the coordination of health and social care.<sup>10 11 15</sup> Such centres provide preventive services, acute and chronic care, and are seen as the first point of contact for most people within the healthcare system.<sup>11</sup>

**Long waiting times in the public sector drive people to seek private healthcare.**<sup>10</sup> Waiting times for surgery, diagnostic procedures and specialist appointments can be significant, and are a growing problem.<sup>10 11</sup> One reason for this may be limited capacity in the healthcare system. Initiatives are underway to reduce waiting times, but in some ACs demand continues to exceed supply,<sup>10</sup> and variations in staffing and waiting times persist.<sup>10</sup>



**An ageing population with increasing comorbidities will challenge the resourcing of the health and social care systems.** Spain has the highest life expectancy in the European Union, and demand and expenditure for health and social care are expected to rise as the population ages.<sup>10 11</sup> Care is predominantly planned around acute illness, and there is often limited support for people with long-term conditions and disability. For example, there are more doctors and fewer nurses in Spain than the EU average, and fewer formal long-term care workers than the OECD average.<sup>10 11</sup> This distribution of healthcare workers may challenge provision of long-term care in the community and effective management of chronic conditions.





# MS POLICY LANDSCAPE

**The National Strategy for Neurodegenerative Diseases outlines ambitions for health and social care in MS, and is considered important in ensuring equal access to care.**

The National Strategy describes clinical features of MS, diagnostic criteria and treatment in Spain; it also outlines the societal costs of MS and core services that should be available to people with MS.<sup>16</sup> Experts identify the key challenges as appropriate funding, implementation and follow-up. Many of the gaps in access to rehabilitation, support and high-quality integrated care are deemed to be driven, in part, by lack of implementation of the national plan.

**The Recommendations for a National Strategy on MS elaborate on the National Strategy and outline key actions to deliver its objectives.** The recommendations include carrying out integrated MS planning and monitoring in every AC, ensuring adequate human resources for interdisciplinary management in both the health and social care systems, developing coordinated MS care pathways and establishing a national MS registry.<sup>17</sup>

**Spain does not have a centralised national MS registry.**<sup>18 19</sup> There are currently many MS databases but they are typically organised in clinical centres or at a regional level.<sup>17</sup> The absence of a national-level registry has hampered monitoring and evaluation of care services and regional benchmarking.<sup>17</sup> There is hope that a Europe-wide project to share information between different MS disease registries will help with unifying the existing data in Spain.<sup>13</sup>

**Spain's two national MS patient associations address unmet needs from the public system.** The Asociación Española de Esclerosis Múltiple (AEDEM-COCEMFE) and Esclerosis Múltiple España (EME) are actively involved in awareness-raising, advocating patients' rights, supporting research and providing information and support to people with MS.<sup>20 21</sup> Both organisations have national and regional chapters that offer guidance to people with MS, and provide rehabilitation and social care directly at the local level.<sup>13 22</sup>



**Navigating the system of MS care providers can be extremely difficult.** The MS system can be highly complex, encompassing many different public and private providers across health and social care. Coordinating care can therefore be challenging, and the burden of communicating between the health and social care providers is often left to the person with MS.<sup>22</sup> Moreover, as care is organised and reimbursements are processed by each AC, services available in different locations can vary widely across the country, further hindering coordination and access.<sup>11 13 23</sup>

**Ultimately, change must be driven at the AC level.** The National Strategy for Neurodegenerative Diseases is an important step towards a framework for providing high-quality MS care. However, as the majority of health and social care is planned and reimbursed by each individual AC, this is where action must be taken. A clear national framework for MS care and support that can be adapted to each AC could be helpful in driving consistent improvement.

### What policies exist for MS in Spain?

Inclusion of MS in the national non-communicable disease or chronic disease plan	No
Neurological disorders plan	Yes
Inclusion of MS in neurological disorders plan	Yes
National strategy on MS	No
National clinical guidelines	Consensus statement on the treatment of multiple sclerosis by the Spanish Society of Neurology in 2016 – incorporated by the National Strategy on neurodegenerative diseases <sup>16 24</sup>
National MS registry	There are some regional and centre-level databases <sup>17 18</sup>



# ORGANISATION OF CARE

*‘The Neurodegenerative Diseases working group of the Spanish National Health Service has done impressive work in MS. However, there are still important unmet needs for people with MS in Spain, namely resources for rehabilitation, and standardisation and availability of treatments, which persist in the ACs mainly due to local administrative constraints.’*

*Dr Óscar Fernández, Regional University Hospital of Málaga*

**MS care is typically provided in hospital-based MS centres, but people may travel significant distances for the most specialised care.** MS centres manage and provide all specialised care including diagnosis, provision of DMTs and symptomatic therapies, relapse treatment and ongoing follow-up. Options for care depend on where the person with MS lives. The Ministry of Health has designated 12 hospitals across Spain as Reference Centres, Services and Units (RCSU) that provide highly specialised care to people with MS.<sup>16</sup> If there is no RCSU in their AC, people with MS can choose to travel to one in another area or be seen at their local hospital.<sup>22</sup> Traveling to an RCSU, even within the person’s AC, may result in significant costs and can be difficult depending on the person’s level of disability. Many people with MS are followed in large MS centres;<sup>25</sup> these non-RCSU hospitals often provide high-quality care.<sup>22 26</sup>

**The size of the hospital that hosts an MS centre often dictates the number of specialist healthcare professionals working there.** In larger centres and RCSUs, people with MS typically receive coordinated care from a broad interdisciplinary team, including an MS specialist neurologist, MS nurses, neuropsychologists and specialists for managing MS symptoms.<sup>25</sup> In smaller hospitals, however, people are often cared for by a generalist neurologist, who may not have expertise in MS. Access to specialised care thus varies between ACs depending on whether there are large hospitals or RCSUs, and there is also significant variation between urban and rural areas.

**Access to rehabilitation is frequently suboptimal.** While post-acute inpatient rehabilitation is reimbursed by national funding, specialised rehabilitation care for MS not always fully reimbursed.<sup>13</sup> Some ACs can provide partial or full reimbursement for rehabilitation, but this depends on local arrangements with providers and the financial circumstances of the AC.<sup>27</sup>

## Timely diagnosis and personalised treatment

*‘Spain’s public health system is good, but there is still some inequity regarding access to specialised medical care, treatment and social resources. Proper referrals to grant this access are needed.’*

*Dr Yolanda Higuera, Hospital Gregorio Marañón*

**Once MS is suspected, the diagnostic pathway is relatively smooth.** The first point of contact is the general practitioner (GP), and if MS is suspected a referral will be made to the neurology department of the closest hospital for testing and diagnosis.<sup>11</sup> An international survey suggested that Spain has one of the shortest intervals between first symptoms and MS diagnosis.<sup>8</sup> Timely diagnosis is enabled by the large number of hospitals and neurologists.

**Some people with MS still experience delays between symptom onset and diagnosis.**<sup>28 29</sup> This may be due to low recognition of MS symptoms by both the person with MS and the GP, particularly if there are unusual or non-specific symptoms.<sup>30</sup> Furthermore, variations in hospital resources and challenges to communication between different actors may affect the waiting time for specialist consultation and eventual diagnosis. For example, in larger MS centres and RCSUs, the wait may be around two weeks, while in smaller centres it could be a month or more.<sup>25</sup> Magnetic resonance imaging (MRI) is an important diagnostic test, but waiting times are significant and in some ACs may exceed one year, thus delaying diagnosis.<sup>29</sup> Such delays can be emotionally taxing for the person with MS and their family.<sup>31</sup>

**Upon diagnosis, people with MS and their families need psychological support and clear information about MS – but access to support varies widely.** A diagnosis of MS can be life-changing, and neuropsychologists are essential in the assessment of cognitive symptoms and provision of long-term psychological support. However, across all stages of diagnosis and MS management in Spain, neuropsychologists can be very difficult to access.<sup>25</sup> To meet this significant need, many people receive care from patient organisations or private providers, usually requiring out-of-pocket payment.<sup>25</sup> Palliative care specialists can also play a role in supporting people with MS and their families from the point of diagnosis, but their integration in MS care is relatively limited.

## Pharmacological management of MS

*‘There is little information about the differences between the individual ACs’ prescription practices, for example annual consumption of medicines or even medication management systems. Research into regional differences would be invaluable to understand and rectify any variations.’*

*Dr José Luís Trillo, Department Valencia Clinico-Malvarrosa*

### **Disparities in reimbursement and eligibility criteria drive regional variations in care.**

The National Strategy for Neurodegenerative Diseases and Spanish Neurology Society clinical guidelines outline the available treatments in Spain.<sup>16 24</sup> However, individual ACs impose different approval processes, including:<sup>25</sup>

- additional eligibility criteria for DMTs beyond those set by the European Medicines Agency or national clinical guidelines
- bureaucratic approval processes which delay access to early treatment with DMTs or use of second-line treatments
- cost-containment strategies that delay a switch from first- to second-line treatments and restrict access to more expensive symptomatic therapies.

**People with MS may struggle to access symptomatic therapies.** Lack of input from rehabilitation specialists may challenge use of symptomatic therapies,<sup>22 23</sup> and co-payments can be significant in some settings. Certain symptomatic therapies are provided in hospital pharmacies and require no out-of-pocket payments.<sup>14</sup> However, in community pharmacies, there may be co-payments for certain treatments,<sup>22</sup> creating a financial burden for people with MS.<sup>32</sup> If the person has retired or receives disability benefits, co-payments are reduced but may still be impactful.<sup>25</sup>

### **What pharmacological treatments are available in Spain?**

Availability of symptomatic therapies	Some symptomatic therapies are provided by the neurologist or MS centre free of charge. <sup>33</sup> Others are paid for at the community pharmacy, with costs reimbursed proportionately according to the person’s salary or employment status <sup>33</sup>
Availability of DMTs	All approved by EU, but each AC may have differing access and availability <sup>34</sup>
DMT reimbursement	100% reimbursement at the national level <sup>34</sup>

## Interdisciplinary and coordinated care

*‘Support and treatment must be granted during all different MS scenarios and stages. To guarantee this, the neuropsychologist, clinical psychologist and rehabilitation physiotherapists must join neurologists and nurses and be part of the interdisciplinary team.’*

*Dr Yolanda Higuera, Hospital Gregorio Marañón*

**Only a minority of people with MS have access to truly interdisciplinary and integrated MS care.** Interdisciplinary teams are typically provided only in large MS centres, which often have enough resources to act as a local hub for the care of people with MS. For example, large centres are more able to support access to neuropsychologists, MS-specialist rehabilitation professionals, specialists for the various MS symptoms and social care.<sup>22</sup> They also coordinate closely with the local MS association chapters. For people in rural areas or with only smaller hospitals nearby, such care is extremely difficult to access. The uneven distribution of interdisciplinary teams and MS centres means that some people do not receive such care or must travel significant distances.<sup>22</sup> Telemedicine and telepharmacy have potential to help improve efficiency in care and reducing these geographical inequalities.<sup>22 35</sup>

**Nurses are considered important in providing high-quality MS care.** Specialist nurses play a key role in providing education to people with MS, supporting adherence to treatment and, in some cases, assessing value and impact of therapies.<sup>36</sup> They are also well placed to support navigation through the healthcare system and coordinate care between different providers.<sup>36</sup> However, the role of specialist nurses is not developing in the same way, or at the same pace, in all ACs, which leads to variations in access and support provided.<sup>37</sup> Primary care nurses, who are often the first point of contact with the healthcare system, also play an important role in the lives of people with MS.<sup>36</sup>

**Access to specialised MS rehabilitation is often suboptimal in Spain.** An EME survey showed that 57% of people with MS do not receive rehabilitation, and among people who do, 32% receive physiotherapy and 16% receive psychological support.<sup>9</sup> Other types of rehabilitation such as occupational therapy, cognitive therapy and speech therapy are less frequent. The majority of people do not receive rehabilitation from the public system, and patient associations and the private sector often address this unmet need.<sup>13</sup> One 2017 report showed that of people with MS who had rehabilitation, 43% received rehabilitation from patient associations and 34% from private centres.<sup>9</sup>

**Cultural and organisational factors contribute to poor access to specialised MS rehabilitation.** Inpatient rehabilitation is generally organised around the needs of patients receiving orthopaedic or acute care, and is not necessarily appropriate for people with MS.<sup>25</sup> However, such approaches may be the only rehabilitative option available in some areas. Moreover, some healthcare professionals may see rehabilitation as a ‘post-acute’ intervention and method to recover function, and thus unsuitable for people with MS.<sup>23</sup> This lack of a ‘rehabilitation culture’ has been reflected in a survey of people with MS, in which 52% reported that their neurologist never suggested rehabilitation and 10% did not know that it could be suitable for their needs.<sup>9</sup>

**Other reasons for poor access include lack of appropriate reimbursement and evidence for rehabilitation.** There is a historical lack of high-quality evidence supporting rehabilitation, which underpins the lack of consistent reimbursement and access to rehabilitation for MS across Spain.<sup>22</sup> As different ACs reimburse different rehabilitation roles or services, the types of roles and services available vary.<sup>23</sup> The lack of comprehensive reimbursement means people with MS often pay out-of-pocket for rehabilitation, either partly or entirely.<sup>23</sup> One survey showed that 6% of people with MS did not receive rehabilitation as they could not afford it.<sup>9</sup>

### How many specialist interdisciplinary services for MS are available in Spain?

Number of interdisciplinary MS clinics	12 RCSUs across the country <sup>16</sup> and approximately 100 MS centres
Number of specialist rehabilitation services	There is very limited national information available <sup>37</sup>
Number of neurologists and MS specialist neurologists	Approximately 3,000 neurologists Approximately 250 MS specialist neurologists <sup>34</sup>
Number of specialist nurses	There is no official specialised MS training for nurses in Spain; however, there has been significant demand for the EMSP Nurse Pro in Spain and a specialist nurses group. <sup>38</sup>



## Monitoring and long-term follow-up

*‘In many places in Spain, high-quality MS medical care is provided seamlessly. However, there are wide local variations in access to rehabilitation and social care and the differences are particularly stark between rural and urban areas.’*

*Dr Jaume Sastre-Garriga, Multiple Sclerosis Centre of Catalonia (Cemcat)*

**Follow-up and monitoring are generally good in Spain, but frequency may depend on the size of the MS centre.** One survey found that 68% of people with MS saw a neurologist at least every six months.<sup>9</sup> However, waiting lists for MRIs can be significant, which may hinder the adequate assessment of MS during these appointments.<sup>29</sup> Larger centres have more resources and often have nurses specifically trained in monitoring and follow-up processes, increasing capacity and allowing for greater frequency of appointments.<sup>25</sup> Smaller centres, however, may have delays and waiting lists due to lack of resources and capacity.

**The transition from care under a specialist MS neurologist to primary care is challenging.** When a person with MS is no longer on DMTs or has high levels of disability, they receive most of their care from primary care practitioners rather than at MS centres.<sup>11</sup> This transition can be difficult,<sup>27</sup> with people at risk of ‘falling through the gaps’ or feeling neglected, as primary care practitioners may have less knowledge or be unprepared to manage people with MS. However, as social care is typically organised through primary care centres, there may be increased access to social care and support when a person with MS transitions away from the MS centre.<sup>25</sup>

## Adaptable support in daily life

*‘Too many rehabilitation and social care services for MS are provided and promoted only by MS patient associations, often offering different packages of support. People with MS and their families may then face challenges of access, depending on where they live.’*

*Dr Jaume Sastre-Garriga, Cemcat*

**Access to social care varies across Spain, depending on the AC.** The Spanish social protection system provides various types of support, including:

- support to find and maintain employment
- financial benefits to compensate for reduction or loss of employment and to pay for long-term care
- access to domiciliary care teams for home aids and/or care in residential services
- tax discounts, such as tax relief on home adaptations.

However, as most social care is organised and reimbursed at the municipal level,<sup>37</sup> there are differences in what is available based on where the person with MS lives.<sup>14 22 23</sup> These variations can make it challenging for people with MS and their families to understand what support is available to them.<sup>22 23</sup>

**Due to limited social care, informal care plays a significant role in Spain.** Community support and services provide a comparatively small proportion of the care in Spain for all but the most advanced cases of MS.<sup>7</sup> For example, most people who receive care in residential facilities do so at significant personal cost, as publicly funded places in residential and day centres are limited.<sup>25</sup> Many people with MS receive informal care at home, rather than in a facility. The costs for informal care can be particularly high in Spain, representing up to 27% of the costs for people with advanced MS.<sup>7 25</sup> This is much higher than in other countries in Europe that also lack formalised services for long-term care, which may be driven by the strong family culture in Spain and family members providing this unmet need.<sup>8</sup> However, caring for a person with MS can have a significant psychological and economic toll.<sup>31</sup>

**Disability assessments do not reflect the realities of MS and, as a result, people in early phases of MS may not receive appropriate support.** In order to receive benefits, a person must be assessed to have a minimum disability level of 33%. However, many people with a recent diagnosis of MS do not reach this certification,<sup>13</sup> and are thus ineligible for employment or support services. The scales used to measure disability do not adequately measure 'invisible' symptoms such as fatigue and depression, nor their progressive or unpredictable nature. Furthermore, assessors may not always understand the nuances of MS. Early access to social care support can be extremely helpful for the person and their family to learn how to adapt to life with MS. To ensure support is accessible when needed, patient associations and clinicians are advocating for people with MS to be automatically certified with 33% disability as soon as they receive their diagnosis.<sup>13</sup>

**Social care in Spain is not adaptable to the changing needs of MS.** People with MS may have sudden onset of new symptoms or progression of disability, which results in new social care needs. This, along with insufficient training, has made disability assessments quite challenging for social workers.<sup>31</sup> Moreover, it can be onerous for a person with MS to navigate the different providers of the social support they need.<sup>22</sup> The burden of adapting to these new and changing requirements may therefore fall primarily on informal carers and family members.

**Maintaining employment is difficult for people with MS, but greater emphasis on workplace adaptations may be helpful.** Employment of people with MS in Spain is particularly low compared with the rest of Europe,<sup>8</sup> likely compounded by high national unemployment levels over the last decade.<sup>11</sup> Implementation of workplace adaptations is often poor,<sup>23</sup> meaning people with MS are not adequately supported to remain in work. Organisational adaptations such as maintaining a comfortable workplace temperature and reducing working hours could help people with MS remain in employment.<sup>8,9</sup>

**The 2008–2014 financial crisis may have challenged the implementation of legislation in Spain to support people with disabilities.** Laws that ensure access to services and long-term care are important advancements in the rights of people with disabilities and their families. However, pressures on the economy may have impacted enactment of such laws. This has led, for example, to reductions in funding for implementation of national or AC regulations, alongside limited supply of services and infrastructure for long-term care across Spain.<sup>13,39</sup>

### What patient groups exist in Spain?

National patient groups	EME – Esclerosis Múltiple España <a href="https://www.esclerosismultiple.com/">https://www.esclerosismultiple.com/</a>  AEDEM-COCЕМFE – Asociación Española de Esclerosis Múltiple <a href="https://aedem.org/">https://aedem.org/</a>
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## Case study 1

### FEDEMA Children's Stories<sup>40</sup>

MS impacts every member of the family, including the person's children. In an effort to explain how the disease may affect their parents, Federación de Asociaciones de EM de Andalucía (FEDEMA) has produced two short stories for children, *What's wrong with Mom?* and *What's wrong with Dad?* The illustrations and simple language help children understand their parent's condition. The stories of people living – and parenting – with MS can send a positive and hopeful message for the whole family. They are available for free online, and hard copies may be requested from FEDEMA.



## Case study 2

### **AEDEM-COCEMFE Home Assistance Programme<sup>41 42</sup>**

Many people with MS may feel isolated or struggle to maintain independence, particularly as disability increases. AEDEM-COCEMFE's Home Assistance Programme (Programa de Ayuda a Domicilio; PAD) coordinates home care for people with MS across Spain. It supports people with MS to maintain their independence and provides assistance in accessing services and navigating the support available in their area. In 2019, PAD coordinated 39 professionals – including social workers, psychologists, physiotherapists, speech therapists, occupational therapists and home attendants – to support 371 people with MS. The initiative is funded by the Ministries of Health, Consumer Affairs and Social Welfare.

## Case study 3

### **EME conference 'Link EM'<sup>43</sup>**

When addressing a complex chronic disease like MS, it is invaluable to have common spaces for professionals and families to exchange ideas and learn from one another. Since 2016, EME has been hosting Link EM, a multi-platform, interdisciplinary conference which brings together healthcare professionals, researchers, organisations, and people living with MS and their families. Its slogan, 'Know, connect and innovate in multiple sclerosis', highlights the ambition to identify and address the neurorehabilitation needs of people with MS. The annual conference takes place over multiple days and offers streaming services for those who cannot attend in person.



# APPENDIX: ABOUT MS

**MS is a complex and progressive disease of the central nervous system**, where the immune system destroys brain, optic nerve and spinal cord tissue.<sup>1-3</sup> As a result, people with MS develop irreversible motor-disability and cognitive impairment over time.<sup>1 44 45</sup> MS affects almost every aspect of day-to-day life,<sup>46 47</sup> and its personal and economic impacts grow significantly as the condition progresses and disability worsens.<sup>3 48 49</sup>

## **There are four main types of MS:**

- **Clinically isolated syndrome (CIS)** is the first clinical presentation of inflammation or lesions.<sup>50</sup> However, many people with CIS will not go on to develop MS.<sup>51</sup> If CIS becomes clinically active and fulfils the current diagnostic criteria, it can be reclassified as relapsing and remitting MS.<sup>50</sup>
- **Relapsing and remitting MS (RRMS)** is characterised by intermittent ‘relapses’ (sudden onset of MS symptoms and disability), followed by remission periods where symptoms abate.<sup>52 53</sup> Approximately 85–90% of people with MS have RRMS at diagnosis.<sup>2 52</sup>
- **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.<sup>50</sup>
- **Primary progressive MS (PPMS)** is where disability accumulates without relapses from the outset.<sup>50</sup>

**MS can be a challenging condition to manage, due to its unpredictability and people’s changing healthcare needs.**<sup>54</sup> 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.





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