

# MS in Europe: the value of integrated and personalised health and social care approaches

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## **Current situation (1-2 pages).** Aprox. 5000 characters (spaces included)

Neurological disorders are among the world's leading causes of poor health and disability.<sup>1,2</sup> Europe, in particular, has a high burden and frequency of brain disorders including multiple sclerosis (MS).<sup>3</sup>

MS is a complex and progressive disease of the central nervous system that places unique challenges upon European health and social care systems. Affecting more than 700,000 people in Europe,<sup>4,5</sup> MS is the leading cause of disability in young and middle-aged people.<sup>6,7</sup> The personal and economic impact of MS rises significantly as the condition progresses and disability worsens.<sup>4,8,9</sup>

The young age of onset and unpredictability of MS means that people may find it very challenging to maintain work and a social life.<sup>3,9-11</sup> This can impact personal financial security and independence; it also places a significant burden on social welfare systems and challenges productivity.<sup>4,7-11</sup> There are considerable informal care costs which largely fall outside of the health and social care systems, borne by people with MS and their families.

There is no cure for MS, thus management focuses on slowing the progression of disability and reducing the impact of symptoms.<sup>8</sup> In recent years, treatment has become increasingly multifaceted requiring multidisciplinary input and regular monitoring, with adaptable and person-centred approaches. MS can be a challenging condition to manage due to each person's unpredictable and changing healthcare needs. Although many effective interventions exist, there are many gaps in both health and social care for people with MS across Europe.

### *Diagnosis and personalised treatment*

Delays to diagnosis and initiation of treatment can cause irreversible disease progression and poorer outcomes for people with MS. Personalised treatment should span disease-modifying therapies (DMTs), rehabilitation, symptom management and secondary prevention tailored to each person and their specific needs and goals. However, across Europe, many people with MS face significant delays to diagnosis and initiation of treatment, or do not have access to all treatment options – often based on cost and where they live.<sup>4 8 10-13</sup>

### *Multidisciplinary care*

Multidisciplinary approaches are essential to providing personalised and adaptable care for all people with MS.<sup>7 14 15</sup> However, access to multidisciplinary care is highly variable across Europe, particularly for specialist nurses and rehabilitation specialists.<sup>4 7 10-12 14 15</sup> Many roles are not accessible in the public healthcare system or well-integrated into MS programmes.

### *Support in daily life*

Supporting and caring for someone with MS can place a significant emotional and financial burden on family members.<sup>16</sup> However, there is often limited support available to help people with MS and their families, resulting in many unmet needs for social, financial and practical support. Without government support, families often must turn to MS societies and patient organisations or face these costs themselves.

### *Support at work*

A high proportion of people with MS are not in work, and those who do work are often part-time.<sup>17</sup> There are many potential workplace adaptations that could help people with MS stay in work, but their usage varies significantly. Because of this, approximately half of people with MS are unemployed three years after diagnosis, rising to 70% after 10 years.<sup>11 17</sup>

There have been many recent efforts to raise awareness of unmet needs and highlight inequalities in MS health and social care at the national and international level. One example of this is the European Brain Council (EBC) *Value of Treatment* report,<sup>18</sup> which identified areas for urgent action to reduce the personal, societal and healthcare burden of brain disorders across the European Union. The dedicated section on MS was developed by a working group consisting of clinical and patient experts from across Europe. It identified significant gaps in provision of care in Europe and highlighted the importance of early intervention, integration of health and social care systems, and the value of secondary prevention of progression as part of a holistic and comprehensive approach to treatment.

## **Future challenges (2-3 pages).** Aprox. 8.500 characters (spaces included)

MS impacts almost every part of society and requires a comprehensive, integrated policy response. Without targeted action across Europe, MS will pose many additional challenges to healthcare and social care systems in the future.

### *The MS population is growing and ageing*

Life expectancy is increasing for people with MS, partly due to improving management strategies.<sup>3 6</sup> It is essential that we consider how to effectively manage a growing MS population with increasing disability and age-related comorbidities.<sup>3 9</sup>

### *Access to treatment care and specialists is hugely variable*

Where a person lives or their ability to pay often affects what type of MS care they receive.<sup>4 10-12</sup> We need to explore innovative ways to reduce these inequalities and ensure that all people with MS have access to a specialist multidisciplinary team providing all treatment and care options.

### *People with progressive MS rarely have their healthcare needs met*

People with progressive forms of MS are rarely seen by a MS specialist or multidisciplinary team, despite having significant health and social support needs. It is important that we continue to explore DMT options and other ways to better meet the needs of progressive MS.<sup>19</sup>

### *Disability and social care assessments fail to capture the full picture*

Tests to assess disability and social care needs rarely reflect the realities of life with MS. For example, fatigue and cognition issues and the relapsing/remitting nature of symptoms are rarely taken into consideration.<sup>8-10 12 14</sup> We need to better assess the totality of the MS experience to ensure that people with MS and their families receive the support that they need.

### *Health, social and rehabilitation care systems are not well integrated*

When different systems are poorly integrated, people may 'fall through the gaps in care' and not receive the specialised support they need. Lack of integration is a common issue in many healthcare systems, and MS provides a particular requirement to include social care in the drive for integration.

To tackle some of these challenges, the EBC and The Health Policy Partnership are building on the findings of the *Value of Treatment* report and developing a consensus around practical and sustainable policy responses to MS at the European level and in Denmark, Italy, Romania and Spain. By taking a pan-European view of healthcare and social services, identifying best practice and national priorities, we aim to create greater

visibility for the unmet needs experienced by people with MS, with a particular focus on:

- 1) diagnosis and personalised treatment and care
- 2) multidisciplinary and person-centred approach to care
- 3) participation in daily life.

With this, we will build a framework for policy change that is relevant to the very different national contexts across Europe, both now and in the future. This work will culminate in the launch of a policy report and national brain-plan templates at the European Parliament in Brussels on 6th November 2019.

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