MS Brain Health

Brain health – time matters

Multiple sclerosis (MS), neuromyelitis optica spectrum disorder (NMOSD), myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD) and related conditions

2024 Report Executive Summary

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This publication and the full report are available online at **www.msbrainhealth.org** or can be accessed by scanning the QR code.

Executive summary

Multiple sclerosis (MS), neuromyelitis optica spectrum disorder (NMOSD) and myelin oligodendrocyte glycoprotein antibody-associated disease (MOGAD) are related, lifelong diseases. There are no cures and, particularly when undiagnosed, misdiagnosed or not treated early and effectively, they can severely affect many aspects of people's lives.

This report builds on our 2015 policy report, *Brain health: time matters in multiple sclerosis*, to include advances made in our understanding of MS and encompass improvements in practice standards, policy developments and emerging science. As per the 2015 report, the authors recommend specific actions to achieve the best possible outcome for people living with these diseases and the overarching theme remains clear – to act early and take a person-centred approach to care, regardless of geographic or economic barriers.

Therapeutic strategies for each of the three diseases that offer the best chance of minimizing ongoing disease activity early in the disease course need to be widely and urgently adopted. When disease activity is not addressed early, increasing disability – such as difficulty walking and vision problems – risks imposing a heavy burden on people and their families. This leads to substantial economic losses for society, due to diminished tax revenue and increasing care costs that could have been avoided. It is bad health economics.

Timely diagnosis is therefore of critical importance, alongside early treatment initiation with effective therapies. People often face considerable delays in diagnosis and treatment initiation, and the non-specific nature of symptoms can contribute to misdiagnosis. Actions to avoid protracted diagnostic journeys such as the right to additional opinions, increased access to specialists and awareness among referring clinicians, and improved access to specialized diagnostic procedures are needed.

Despite outstanding progress in research and development into treatment and detection innovations, treatment access remains limited in many countries. Regulatory bodies, healthcare authorities, payers and budget holders can all help to improve early access to effective therapies that offer optimal treatment outcomes (also known as 'flipping the pyramid'). Relevant bodies need to consider the costs to all parties when conducting economic evaluations, and support research and development into novel therapeutic strategies.

Effective and regular monitoring of disease activity and the formal recording of this information forms a cornerstone of the treatment strategy recommended by the authors. Paying close attention to comorbidities (including depression), lifestyle factors and modifiable brain health drivers, and monitoring visible and hidden symptoms of disease worsening or progression, such as cognitive changes, are part of an optimal approach to care. The results of clinical examinations and brain scans will enable personalized treatment for every patient. Standardization of these outcomes can also generate long-term real-world evidence that can be used to evaluate therapeutic strategies, and should set the outcome targets to which relevant stakeholders should be held accountable.

But most critical is to involve people proactively in shared decision-making and empower them to manage their diagnosis through holistic care and to adopt a lifestyle that maximizes their brain health (e.g. not smoking, keeping as active as you can, improving sleep). The goals should be to provide a person-centred, integrated approach to care, not forgetting about the key role disease-specific peer support and community organizations can play, and to direct patients and their families to them as standard practice.

In this report, the author group presents a thorough set of recommendations and the rationale for them with the hope that strong political will and societal commitment will improve the outcomes for all people with MS, NMOSD and MOGAD. Enabling and promoting widespread adoption of these recommendations has the potential to maximize lifelong brain health. The key is to start somewhere; even small changes can make a difference to individuals, families, societies and economies.

Recommendations

Not every nation, community and institution will achieve all recommendations. The key is to start somewhere; even small changes can make a difference to individuals, families, societies and economies.

Minimize delays in the diagnosis of MS, NMOSD and MOGAD and in the time to treatment initiation

Education

- Ensure that education of HCPs and further/specialist education of family and primary care physicians, emergency staff and opticians include knowledge of all potential symptoms and the importance of prompt referral to specialist neurology services.
- Ensure that the curriculum for HCPs relating to MS knowledge includes the risk of misdiagnosing MS in people who have NMOSD, MOGAD or a related disorder.
- Ensure HCP education helps HCPs to ask their patients the right questions, especially about hidden symptoms, to ensure the best possible two-way dialogue and shared decision-making.

Specialist services

- Improve access to general and specialist neurology care. In parallel, invest in community-based services.
- When possible, promote the delivery of integrated care via Neuroimmunology Care Units or other kinds of specialized care centres, centres of excellence or comprehensive care centres.
- Improve the availability of diagnostic tools such as MRI scanners and internationally standardized protocols to expedite the diagnostic process.
- Strive to increase the number of doctors, nurses and other HCPs who specialize in the management of MS, NMOSD and MOGAD.
- Leverage digitalization and AI to ensure remote access to specialist knowledge and care.

Treatment principles

- Ensure national guidelines align with international guidelines for diagnostic criteria and treatment management targets, including early treatment and early access to more efficacious treatments.

Advocacy and information

- Support local, national and regional patient advocacy groups.

See every patient as a person and ensure an optimal approach to care

Holistic and shared care

- Enable an integrated care approach.
- Ensure a person-centred approach is reflected in public health policy, guidelines, budgets and other political texts that provide political accountability.
- Ensure the right to and practical availability of specialist care and additional opinions.
- Mandate a shared decision-making process.
- Ensure the reliable presence of necessary interventions and make the full range of DMTs available to people, regardless of their treatment history and diagnosis.
- Mandate the inclusion of lifestyle prescriptions, which HCPs need to support people to live a brain-healthy lifestyle.
- Ensure that HCPs and, when appropriate, patients are resourced to monitor disease activity in people with MS, NMOSD or MOGAD, taking advantage of AI and other innovative technology approaches when possible.
- Ensure that patients and, if appropriate, caregivers are educated about visible and hidden symptoms of disease worsening or progression following diagnosis.
- Ensure equity of rights and opportunities, including personal safety protection, social care, disability and employment rights regardless of sex, gender, race, ethnicity, age, level of disability or socioeconomic status.

Data collection and monitoring

- Agree and implement standardized data collection techniques, protocols and data sets (nationally and internationally) to track clinical and subclinical events in routine practice.
- Allow for the consistent availability of treatment for as long as it provides benefit. In the case of a suboptimal response, HCPs and patients can make a prompt decision about whether to switch therapy in a shared decision-making process.
- Promote cross-border collaboration on research.

Consult the most robust evidence base possible and generate further evidence to make good decisions about therapeutic and management strategies and access to care for people with MS, NMOSD and MOGAD

Value to society

- Ensure affordable treatments: people with life-changing diseases should be able to access crucial interventions without financial hardship.
- Improve access to vocational rehabilitation and/or supported employment, assisted living and disability benefits.
- Include a societal perspective encompassing the full scope of patient and caregiver burden in all economic evaluations of healthcare interventions.
- Encourage resource investment into approaches that reduce the long-term costs of managing and living with MS, NMOSD and MOGAD.
- Support public registries that capture care and social services data, allowing all stakeholders transparent access to relevant findings from real-world data.

Self-monitoring and self-management

- Support patient engagement and self-management through information, PROMs and patient-reported experience measures.
- Establish harmonized approaches, such as a registry for secondary uses of patient data.

AI, artificial intelligence; DMT, disease-modifying therapy; HCP, healthcare professional; MOGAD, myelin oligodendrocyte glycoprotein antibody-associated disease; MRI, magnetic resonance imaging; MS, multiple sclerosis; NMOSD, neuromyelitis optica spectrum disorder; PROM, patient-reported outcome measure.

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