



Recommendations for
**Caregivers of
Children and
Adolescents
with MS**

TABLE OF CONTENTS

2 TABLE OF CONTENTS

6 COMMITMENT, AWARENESS,
COORDINATION

3 INTRODUCTION

7 TAKE ACTION

4 THE SCOPE OF THE
RECOMMENDATIONS



The European Multiple Sclerosis Platform (EMSP) represents more than 1 million people living with multiple sclerosis (MS) in Europe through its network of 43 member societies in 37 European countries. EMSP's activities are directed at improving the quality of life of people with MS, as well as access to treatment, care, employment and adequate support.

One of the key priority actions of the EMSP's Code of Good Practice is to develop a better understanding and treatment of paediatric MS, as well as supporting and empowering paediatric MS caregivers.

“There are more than

30,000

cases of Paediatric MS in the 22 countries responding to this question. Given estimates on the total population with MS in Europe and the estimated prevalence of Paediatric MS, this is highly likely to be an underestimate.”

2020 MS Barometer. Brussels: EMSP¹

These “Recommendations for Caregivers of Paediatric Multiple Sclerosis” aim to improve care of children and adolescents with MS by ensuring that their caregivers are better equipped to deal with challenges and receive targeted support within the national system they live. In addition, it allows the identification of gaps in the current support systems, policies, and legislations to provide an optimal support to caregivers of paediatric MS.

Parents or other carers need psychological, informational, and financial support to allow them to best support the child's wellbeing along with their own².



THE SCOPE OF THE RECOMMENDATIONS:

THE AREAS OF PRACTICE OR POLICY THAT SHOULD BE ADDRESSED:

➤ Practices of health service providers

- 1 Improvement of healthcare professionals' practices/consultation models relating to the provision of paediatric MS information, treatment, and symptom management, as well as healthy lifestyle habits.
- 2 Ensure early access to appropriate medications for children with MS, to help slow the progression of the disease.
- 3 Provide information on the symptoms of paediatric MS to the caregivers, including psychologists to avoid a delayed diagnosis.
- 4 Provision of timely access to child neurology services for the caregivers and their families



➤ Psychological services and professionals

The availability and provision of adequate psychological support for families throughout the entire MS journey should be guaranteed, including at the time of diagnosis and when transitioning from child to adult neurology services.





➤ Social services

Access to social support to both caregivers and children and adolescents with MS is essential and should be delivered by the social care systems. This can be facilitated by the community or peer support groups, in addition to the provision of more formal services.

➤ Policy makers and legislators

Financial wellbeing of carers of paediatric MS, should be guaranteed to avoid social isolation. Policies should also address concerns regarding employment and offer flexible working arrangements to facilitate caring responsibilities and offer financial support.



➤ Schools and education providers

Improvement of educational support, including an increased awareness of MS and similar conditions among education providers will allow a better adjustment and integration in society of young people affected by MS.



➤ COMMITMENT

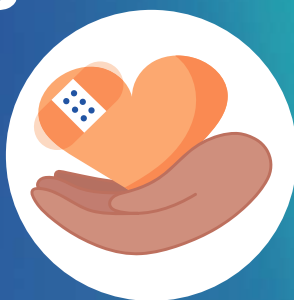
To ensure a better quality of life for children and adolescents with MS and their caregivers, European health and social care systems stakeholders should commit themselves to improve existing practices, policies, and infrastructures.

Across Europe only 16 (46%) countries out of 35 represented in the MS Barometer provide any social support specific to paediatric MS carers and only 18 (51%) provide child disability allowances.



➤ AWARENESS

Policy decision-makers, health and social care providers, educational professionals as well as caregivers should be informed on MS and its impact to implement practices that ultimately benefit the children with MS.



➤ COORDINATION

All stakeholders should work together to ensure the ecosystem of people with MS and their caregivers is personalised and thus, allow a timely response to the needs and challenges faced by the children with MS and their caregivers.

Services and events provide opportunities for young people with MS to connect with a community, learn more about their disease and enjoy time with their family and peers.



Scan or click this QR code to watch our animated video about Paediatric MS

HOW CAN YOU HELP US TO TURN THEM INTO ACTIONS?



If you are a health care professional caring for young people with MS, get involved with EMSP & sign up to our newsletter



If you are a person affected by MS, get involved with your national MS Society

Share our animated video and this report on social media and ask your connections to join you in acting for change



Share our animated video and this report with your MEP and ask for their intervention in your country



to learn more please visit:
www.emsp.org

¹ European MS Platform. 2020 MS Barometer. Brussels: EMSP. URL: www.msbarometer.eu

² Waldman A, Ghezzi A, Bar-Or A, et al. 2014. Multiple sclerosis in children: an update on clinical diagnosis, therapeutic strategies, and research. *Lancet Neurol* 13(9): 936-48, and Harding KE, Liang K, Cossburn MD, et al. 2013. Long-term outcome of paediatric-onset multiple sclerosis: a population-based study. *Journal of Neurology, Neurosurgery and Psychiatry* 84(2): 141-47

³ Waldman A, Ghezzi A, Bar-Or A, et al. 2014. Multiple sclerosis in children: an update on clinical diagnosis, therapeutic strategies, and research. *Lancet Neurol* 13(9): 936-48

⁴ Maguire R, Kasilingam E, Kriauzaite N. 2019. Caring for children and adolescents with multiple sclerosis. Brussels: European Multiple Sclerosis Platform

⁵ Ghai, S., Kasilingam, E., Lanzillo, R., Malenica, M., van Pesch, V., Burke, N. C., ... & Maguire, R. (2021). Needs and Experiences of Children and Adolescents with Pediatric Multiple Sclerosis and Their Caregivers: A Systematic Review. *Children*, 8(6), 445.





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