

EMHA, the European Migraine and Headache Alliance, would like to share this contribution in relation to the European Commission’s preparation of the ‘European Disability Strategy 2020-2030’. Despite its prevalence, migraine remains an invisible disease associated with stigma, discrimination and unnecessary additional suffering.

The migraine community expects this new strategy will bring solutions to their specific needs and take stock of their policy recommendations. Migraine spans from activity limitation or incapacity to disability depending on the stage of the disease. It is important the next strategy fully considers this graduation to help people with migraine be a full part of society and enjoy their human rights to the full.

Table des matières

Migraine: a broadly incapacitating problem.....	1
Migraine is not just a bad headache.....	1
Who is affected ?.....	2
Migraine has a gender bias	2
Migraine is a costly disease.....	2
Challenges faced by people with migraine	2
Misdiagnosis and underdiagnosis	3
Access to treatment.....	3
Education	3
Migraine at work.....	4
Activity limitation rather than disability	4
EMHA’s recommendations	5
About EMHA.....	7
References	7

Migraine: a broadly incapacitating problem

Migraine is not just a bad headache

It is a chronic and debilitating neurological disease presenting repeated attacks: it can be episodic (< 15 days per month) or chronic (≥ 15 days/month). Chronic migraine is a clearly defined subtype of migraine. It usually develops from episodic migraine at a conversion rate of about 3% a year. Risk factors for migraine chronification include overuse of acute migraine medication, ineffective acute treatment, obesity, depression, low educational status and stressful life events. The chronification of migraine is reversible.

Migraine attacks have a range of manifestations: they start with premonitory (prodromal) symptoms with cognitive manifestations, yawning, food craving, passing urine..., moving on to canonical symptoms (pain, nausea, vomiting...) and ending-up in postdrome symptoms (tiredness, concentration problems...) and aura.

Usually starting at puberty, migraine is recurrent throughout life in many cases.

Migraine is recognized as one of the most burdensome diseases. The studies published on the Global Burden of Disease (GBD) acknowledged migraine as the second position in the rank of top causes of Years Lived with a Disability (YLDs) in 2016ⁱ.

The impact of migraine on the quality of life to the individual is comparable or greater than that associated with congestive heart failure, hypertension, or diabetesⁱⁱ. The impact goes

beyond the attacks themselves: numerous studies have shown that migraine impairs a person's ability to function during an attack and diminishes quality of life during – and between – attacksⁱⁱⁱ.

Who is affected ?

In the European Union, 41 million people have migraine^{iv}. Chronic migraine affects between 1-2% of the general population, yet it receives little attention. Adults with a migraine describe episodic attacks with specific features, of which headache and nausea are the most characteristic. In children, attacks tend to be shorter-lasting and abdominal symptoms more prominent. Attack frequency is typically one or twice a month but can be anywhere between once a year and once a week, often subject to lifestyle and environmental factors.

Migraine has a gender bias

Three times more women than men are impacted by migraine^v. The course follows women's reproductive events (from puberty to menopause)^{vi}. The peak is at around 40 years^{vii}.

The studies published in the GBDⁱ confirmed that migraine is more prevalent among females and in both sexes in the most productive age.

Migraine is a costly disease

In the EU, the total annual cost of migraine has been estimated at € 111 billion (64% of all headache costs)^{viii}. As an example, the migraine cost to UK economy is £ 3.42 billion (£ 5-7B for all headaches)^{ix}. The annual per person cost for migraine amounts to € 1,177, 93% being attributed to indirect costs.

Lost working hours and reduced productivity due to migraine are a driver of huge economic losses in the EU: an estimate of the total cost of migraine in Europe is € 27 billion per year^{vi}.

Migraine has direct implications for healthcare systems that could be overcome by effective and cost-effective solutions.

Challenges faced by people with migraine

EMHA's organised a webinar in September 2020 to mark EU Migraine Action Day, a yearly EMHA event to raise awareness about migraine. This year's topic was 'The Missing Lesson' and focussed on the medical curriculum deficit when it comes to migraine. The lack of knowledge about migraine among the healthcare providers is an issue. This is explained by the lack of necessary medical education on migraine: only 4 hours of undergraduate medical education and 10 hours in specialist training are dedicated to headache diseases.

The consequences are high: in Spain, for instance, the delay to have a migraine diagnosis is 6 years, as stated by Prof. Pablo Irimia at 'The Missing Lesson' webinar organised by EMHA and hosted by MEP Aldo Patriciello^x. This was further demonstrated in EMHA's The Truth

Behind Migraine video where people with migraine from different EU countries present their own experience with getting a diagnosis.

Misdiagnosis and underdiagnosis

Worldwide, a large number of people with headache disorders are not diagnosed and treated: only 40% of those with migraine or tension-type headache are professionally diagnosed^{xi}.

Other figures regarding the diagnosis of migraine are striking and all point to the same hurdle to overcome: worldwide, 60% of people with headache disorders are not properly diagnosed^{xii}. The Eurolight study has shown that less than 20% of people with migraine has seen a GP or a specialist^{xiii}, a US study corroborated that most people with migraine have never been diagnosed (almost 70% had not sought medical advice)^{xiv}.

Still worldwide, the lack of knowledge among healthcare providers is the principal clinical barrier: on average, only 4 hours of undergraduate medical education are dedicated to instruction on headache disorders^{xi}.

Access to treatment

Besides access to treatment being hindered by the lack of timely diagnosis caused by the lack of awareness about migraine among the population and the medical profession, the fragmentation of the healthcare system has a deep impact on access to treatment too (or lack of it). Most people with migraine experience a care pathway that is fraught with dead ends, where often optimal care is unavailable, fragmented or difficult to access.^{xv} Even after crossing the first barrier of seeking help, many people with migraine do not receive the best possible care due to unclear care pathways, limited number of headache specialists, or lack of access to the right treatment at the right time. Suboptimal management of migraine leads to increased healthcare system costs due to more frequent emergency care use and specialist visits

Education

Migraine has an impact on children and teenagers school performance: adolescents with migraine aged 13-18 years endure greater impairment in school functioning compared to other children free from migraine^{xvi}. Children with migraine are significantly more likely to present a school performance average below average and poorer academic performance correlated with headache severity and disability^{xvii-xviii}. Headaches are a cause for anxiety, depression and school absenteeism.^{xix}

Having migraine and going to school can be a challenge. Children, parents, teachers and headmasters must join forces to develop approaches that can help avoid migraine triggers and enabling the child to have access to a quiet place deprived of lights for instance. EU funding to support such adaptations must be allocated. All measures that will allow children and teenagers having access to education on par with other children respond to the fundamental right of equal access to education.

Migraine at work

Having migraine leads to job insecurity. Despite work being a contributor to social integration, this is not the case for people with migraine. The work environment can become an occupational risk: work stress, computers, noise, work shifts. This is all too often accompanied by a lack of recognition of the disease and an adaptation of the environment.

Migraine predominantly affects working-age people (females – 18% vs. 6 % males)^{xx} It is the second highest cause of short-term absence (47%)^{xxi}. The ‘My Migraine Voice’ study found that 60% of employed people with severe migraine on average missed a week of work per month^{xxii}.

Talking about migraine in the workplace can be stigmatising: employees worry about how they will be perceived? Will their career be affected? How to overcome the quick judgement that it is just a headache? The line managers do not know about migraine, its severity and impact on the migraineur. Talking about personal matters on the workplace can be embarrassing and not well-perceived.

Next Generation EU, the recovery plan for Europe, is an opportunity for the migraine community to see improvements made to their workplace.

Activity limitation rather than disability

As shown in this paper, there are different levels in migraine attacks and the individual’s ability to go to school or work is greatly impacted by the temporary incapacity generated by the migraine attacks. This requires tailored approaches to make sure the individual does not feel excluded.

Although migraine fits in the definition of disability¹, activity limitation as a dimension of health/disability capturing long-standing limitation in performing usual activities (due to health problems) needs to be considered. This is clearly a concept that needs to be included in the next EU Disability Strategy. The strategy must pay due attention to the situation of people with migraine. Indicators based on this concept can be used to evaluate the general health status, disability and related inequalities and health care needs at the population level.

¹ Disability is conceived as an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between a person’s health condition(s) and that individual’s contextual factors (environmental and personal factors). Migraine does fit in the United Nations Convention on the Rights of Persons with Disabilities definition of disability or the International Classification of Functioning, Disability and Health (ICF) framework that defines measures functioning and disability.

<https://ec.europa.eu/eurostat/statistics-explained/index.php/Glossary:Disability>

EMHA's recommendations

In September 2020, EMHA kicked-off its EU policy advocacy campaign to make migraine a European Health priority. Its policy recommendations towards the EU and national policy makers are embedded in its [Call To Action](#).

Based on these recommendations, the current sanitary and economic context generated by the coronavirus pandemic, the scope of the problem, the urgency to improve the lives of people with migraine and the duty to respect their rights, EMHA would like to invite the European Commission to consider the following topics in the EU Disability Strategy 2020-2030:

- 1. Participation**
 - Ensure people with migraine are considered as full citizens of the EU by removing all barriers to equal participation in society (education, work, social life)
 - Involve people with migraine and migraine associations in the setting-up and implementation of supportive measures
 - Develop Migraine-Friendly Environments
- 2. Equality**
 - Combat discrimination and stigma experienced by people with migraine
 - Remove all barriers to equal participation in society
 - Promote equal opportunities at all stages of life (education, work, social and family life) such as in the mainstream education system and the workplace
- 3. Employment**
 - Recognise that employees and workers with migraine have special needs
 - Implement adapted workplaces that match the specificities of the disease and allow people with migraine to enter and remain in the labour market
 - Raise awareness among fellow workers so they understand the situation and are supportive of friendly workplaces for people with migraine
- 4. Education and training**
 - Prevent school failure by recognising that pupils and students with migraine have special needs
 - Develop an inclusive and quality mainstream education system where pupils and students at risk of failure due to an incapacitating or disabling disease are able to receive a continuous high-quality education
 - Ensure the Erasmus programme is fully compatible to the specific needs of students with migraine
 - Enhance professional training on migraine for all healthcare professionals
- 5. Social protection**
 - Combat poverty and social exclusion that can be triggered by an inadapted education system and workplace

- Implement care pathways tailored to the patient's needs
- 6. Health**
 - Raise awareness about migraine, its specificities and challenges
 - Promote early diagnosis of migraine, access to treatment and equal access to health services and related facilities
- 7. Gender**
 - Include a gender perspective in all incapacity/disability discussions and measures
- 8. Human Rights**
 - Mainstream the rights of people with migraine in all EU policies and recommendations
 - Improve the social and economic situation of people with migraine, building on the Charter of Fundamental Rights of the EU and on the Treaty on the Functioning of the EU
- 9. Sustainable Development Goals**
 - Deliver on the UN Sustainable development Goals, especially goals 1 (no poverty), 3 (good health and well-being), 4 (quality education), 5 (gender equality), 8 (decent work and economic growth) and 10 (reduced inequalities)
- 10. EU support**
 - Mainstream migraine in all policies (Health, social affairs, education, environment, gender...)
 - Make use of the funds provided by the EU Recovery Plan to fill the gaps endured by the migraine community and implement a supportive health, social and education environment

15 January 2021

About EMHA

The European Migraine & Headache Alliance (EMHA) is a non-profit umbrella organization, that includes over 30 patient associations for migraine, cluster headache, trigeminal neuralgia and other headache diseases, across Europe.

The Alliance was launched in 2006. It speaks on behalf of 41 million Europeans living with headache disorders.

EMHA is an active member of the European Federation of Neurological Alliances [EFNA], the International Association of Patient Organizations [IAPO], the European Patients Forum [EPF] and works closely with organizations such as the European Headache Federation [EHF], European Brain Council [EBC].



EMHA - Rue d'Egmont 11 - 1000 Brussels (Belgium)

<https://www.emhalliance.org/>

The Missing Lesson on Instagram :

<https://www.instagram.com/themissinglesson/>

The Migraine Movement

<https://themigrainemovement.com/>

EMHA on Twitter : @EMHAlliance

Facebook : <https://www.facebook.com/EMHAlliance/>

Elena Ruiz de la Torre
Executive Director
elena@emhalliance.org
+ 34 (0)639 66 99 65

Annette Dumas
EU Affairs Associate
annette@emhalliance.org
+ 32 (0)473 22 18 54

References

ⁱ Global, regional, and national burden of migraine and tension-type headache, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016, GBD 2016 Headache Collaborators, *Lancet Neurol* 2018; 17: 954–76
<https://www.thelancet.com/action/showPdf?pii=S1474-4422%2818%2930322-3>

ⁱⁱ Hazard E. et al, The Burden Of Migraine In The United States: Current And Emerging Perspectives On Disease Management And Economic Analysis, *VALUE IN HEALTH*, Volume 12 • Number 1 • 2009

ⁱⁱⁱ Buse D.C. et al., Assessing and managing all aspects of migraine: migraine attacks, migraine-related functional impairment, common comorbidities, and quality of life, *Mayo Clin Proc.* 2009;84(5):422-435 doi: 10.1016/S0025-6196(11)60561-2.

^{iv} Stovner L.J., Andre C., On behalf of the Eurolight Steering Committee, Impact of headache in Europe: a review for the Eurolight project, *J Headache Pain* (2008) 9:139–146- <https://doi.org/10.1007/s10194-008-0038-6>

^v Diamond M., The Impact Of Migraine On The Health And Well-being Of Women, *JOURNAL OF WOMEN'S HEALTH*, 2007, Vol. 16, Number 9

^{vi} Nappi G. et al., Neurophysiology of migraine, *J Headache Pain* (2001) 2:S67–S71

^{vii} Lipton R.B. et al., Migraine prevalence, disease burden, and the need for preventive therapy - *Neurology* 2007, 68:343–349

^{viii} The cost of headache disorders in Europe: the Eurolight project, M. Linde et al., *European Journal of Neurology* 2012, 19: 703–e4, doi:10.1111/j.1468-1331.2011.03612.x

^{ix} World Health Organization. Online Q&A: How common are headaches? 2014.

-
- ^x The Missing Lesson webinar, organised by EMHA and hosted by MEP Aldo Patriciello, 22 September 2020 <https://www.emhalliance.org/publications/>
- ^{xi} WHO Fact Sheet on headache disorders, 2016, <https://www.who.int/news-room/fact-sheets/detail/headache-disorders>
- ^{xii} Steiner T.J. et al., Time to act on headache disorders, *J Headache Pain*. 2011. 12:501–503 <https://doi.org/10.1007/s10194-011-0368-7>
- ^{xiii} Katsarava Z. et al; Poor medical care for people with migraine in Europe – evidence from the Eurolight study; *The Journal of Headache and Pain* (2018) 19:10
- ^{xiv} Diamond M. et al, The Impact of Migraine on the Health and Well-Being of Women; *JOURNAL OF WOMEN’S HEALTH* 2007b, Volume 16, Number 9, 2007
- ^{xv} European Brain Council (EBC), Value Of Treatment, Headache: The patient journey. 2017. <https://www.braincouncil.eu/wp-content/uploads/2017/05/VOT-Poster-Headache.pdf>.
- ^{xvi} Powers S.W. et al, Quality of life in paediatric migraine: characterization of age-related effects using Peds QL 4.0; *Cephalalgia* 2004, 24:120–127..
- ^{xvii} Arruda M.A. & Bigal M. E., Migraine and migraine subtypes in preadolescent children; *Neurology®* 2012;79:1881–1888.
- ^{xviii} Rocha-Filho Pedro A.S. et al, Headaches, Quality of Life, and Academic Performance in Schoolchildren and Adolescents; *Headache* 2014;54:1194-1202
- ^{xix} Rousseau-Salvador C. et al., Anxiety, depression and school absenteeism in youth with chronic or episodic headache, *Pain Res. Manag.* 2014 Sep-Oct; 19(5): 235–240. doi: 10.1155/2014/541618
- ^{xx} Steiner TJ et al. The prevalence and disability burden of adult migraine in England and their relationships to age, gender and ethnicity. *Cephalalgia*. 2003;23(7):519-527.
- ^{xxi} All-Party Parliamentary Group on Primary Headache Disorders. Headache Disorders – not respected, not resourced. 2010
- ^{xxii} Schwedt TJ, Vo P, Fink R et al. Work productivity amongst those with migraine: results from the My Migraine Voice survey. Abstract presented at the 60th Annual Scientific Meeting of the American Headache Society (AHS), San Francisco, CA, USA, June 28-July 1, 2018.