

Call to Action for a comprehensive EU action on migraine

Migraine: a common disease that is widely ignored at EU level

Migraine is not just a bad headache

It is a serious, distinct and complex neurological disease. It is the third most common disease worldwide and a cause for incapacity. This generates a huge clinical and economic burden for both individuals and society.

Migraine is a common and invisible life-span disease

41 million adult Europeans experience migraine in Europe (prevalence : 14%). Migraine often begins at puberty and mostly affects people aged between 35 and 45 years. It is also common in children: about 10% of school-age children and up to 28% of adolescents between 15-19 years. Half of all people affected by migraine have their first attack before the age of 12.

Despite its prevalence and serious human, social and economic impact at European level, migraine is still widely overlooked by healthcare systems and policy makers.

Migraine is a cause of incapacity

Migraine is a disabling disease that generates temporary incapacity during the attacks. It is labelled as the second leading cause of disability in the world and the third in people below 50.

Besides, possible genetic factors or environmental factors (like the work-place) play a significant role in how they affect those affected by migraine.

Migraine continues to be under-diagnosed and therefore under-treated

A minority of people experiencing migraine are professionally diagnosed. In Europe, too few people with migraine consult physicians and specialists, migraine-specific medications are used inadequately even among those who do. There are some barriers to diagnosis: healthcare professionals' knowledge about migraine is low, the general public does not perceive headaches as serious and may not be aware that effective treatments exist.

The lack of robust data is the reason why the scale of the public health problem may be underestimated.

Migraine remains under-estimated, under-diagnosed and under-treated across Europe.

If left unchecked, migraine presents a devastating public health crisis that robs people of their right to work, participate in society and live their lives to the full.

Migraine is a costly disease

Migraine is most troublesome during people's productive years (late teens to 50s). In the EU, the total annual cost of migraine was estimated at \in 111 billion (64% of all headache costs). The annual perperson cost for migraine amounts to \in 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 \in 27 billion per year.

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

The burden of migraine for the healthcare systems can be overcome by effective and cost-effective solutions.



Migraine in the work-place

As migraine peaks during individuals' most productive years of life, sufferers' productivity at work can be cut by half. This represents an important cause of lost work time (17.7% of males and 28.0% of females with migraine can lose over 10 days of activities during a 3-month period). The 'My Voice Migraine' study found that 60% of employed people with severe migraine on average missed a week of work per month.

Discrimination in the work-place is common and support is rare.

Migraine has a gender bias

Migraine has a gender bias: the global age standardised prevalence is 14.4% overall: 18.9\% for women and 9.8% for men.

Migraine is common in children: 8% of boys and 23% of girls will have experienced a migraine by the time they turn 17.

Women have an overall tougher migraine journey: gender, cultural attitudes and socioeconomic norms can further contribute to a different experience of migraine between men and women.

Migraine impacts the individual's quality of life

The extent to which migraine affects patients psychologically may not be fully appreciated.

Depression and anxiety often coexist with migraine. Migraine can be a risk factor for dementia in women, is associated with chronic pain, and chronic pain substantially impacts the risk of memory decline and dementia.

Migraine research must be increased

Despite its prevalence, migraine is often overlooked by key decision makers in terms of funding and research.

It is not exactly known what causes migraines. Research must continue into genetics, environmental factors, lifestyle, brain chemical imbalances, family history and gender.

> The lack of robust data around migraine is the reason why the scale of the public health problem may be underestimated.

EMHA calls upon all national and EU policy makers to fully embrace the migraine challenge and build a supportive environment that will improve the quality of life of EU citizens.



Call to Action for a comprehensive EU action on migraine

EUROPEAN COMMISSION

- Make migraine a EU health, social and research priority
- Ensure neurological disorders like migraine receive due attention in the Commission's current and future work (gender equality, demographic change, pharmaceutical strategy, disability, education, social affairs)
- Include a 'Brain Mission' In Horizon Europe that also looks at migraine
- Dedicate a significant and long-term funding in neurological disorders medical and social research (Horizon Europe, IMI) to fill the migraine knowledge gap

- Ensure all Artificial Intelligence developments at EU level respond to the needs of people with migraine
- Ensure the implementation of the Work-Life Balance Directive positively affects the migraine community
- Ensure migraine is included in the delivery of the European Pillar of Social Rights and the European Semester

EUROPEAN PARLIAMENT

- Support the setting-up of a Migraine Alliance in the EP to raise awareness, influence policies and develop migraine initiatives
- Ensure migraine is enshrined in the EP work on disability, gender equality, demographic change, the pharmaceutical strategy
- Include migraine in the EP work on health (depression, pain, women's health)
- Steer initiatives to better understand migraine, its development, how it affects society as a whole and how to improve the situation
- Help join forces to fight stigma associated with migraine
- Invite MEPs to be migraine ambassadors at EU and national level

NATIONAL GOVERNMENT

- Support migraine awareness campaigns to educate the public about the differences between migraine and headache
- Develop national migraine strategies with the involvement of migraine patient associations
- Ensure access to timely and quality diagnosis and access to available treatments
- Develop and support care pathways that fully address patients' needs
- Improve the medical curriculum to dedicate sufficient time to headache disorders and migraine in particular
- Engage healthcare professionals to better diagnose migraine, discourage self-medication and drug overuse and direct patients to headache services

- Help break the stigma associated with migraine to empower people with migraine and society to be fully inclusive of people with migraine
- Adapt school and work-place legislation to give people with migraine equal opportunities to contribute to society
- Increase migraine research funding to better understand how the disease develops and affects patients and develop treatments
- Support migraine associations as key partners in awareness-raising, professional education, social support and drug development



About EMHA

EMHA is a non-profit umbrella organization with 34 patient associations for Migraine, Cluster Headache, Trigeminal Neuralgia and other headache diseases, across Europe.

The Alliance was launched in 2006. Its aim is to speak on behalf of and to advocate for the rights and needs of the 138 million people in Europe 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 also works closely with organizations such as the European Headache Federation [EHF], European Brain Council [EBC] and others.

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References

Agosti R., Migraine Burden of Disease: From the Patient's Experience to a Socio-Economic View, Headache, 2018; 58 :17-32 First published:26 April 2018 https://doi.org/10.1111/head.13301

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

WHO Headache Disorders Fact Sheet (2016), https://www.who.int/news-room/fact-sheets/detail/headache-disorders

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

Migraine and Research Foundation, https://migraineresearchfoundation.org/about-migraine/migraine-in-kids-and-teens/

Steiner TJ., Stovner LJ., Vos T., Migraine is the third cause of disability in under 50s, J Headache Pain. 2016; 17(1): 104. doi: 10.1186/s10194-016-0699-5 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5108738/

Atlas of headache disorders and resources the world 2011 (2011), WHO _ Lifting the Burden https://www.who.int/mental_health/management/atlas_headache_disorders/en/

Katsarava Z., Mania M., Lampl C., Herberhold J., Steiner T.J., Poor medical care for people with migraine in Europe – evidence from the Eurolight study, J Headache Pain. 2018; 19(1): 10. https://doi.org/10.1186/s10194-018-0839-1

M. Lindea et al., The cost of headache disorders in Europe: the Eurolight project, European Journal of Neurology 2012, 19: 703–e4, https://doi.org/10.1111/j.1468-1331.2011.03612.x European Brain Council, Migraine Fact Sheet, http://ebc-brussels.org/wpcontent/uploads/2015/07/Migraine-fact-sheet-Sept-2011.pdf

The Value of Treatment for Brain Disorders, Policy Paper – Towards Optimizing Research and Care for Brain Disorders, European Brain Council, (2017) https://www.braincouncil.eu/wp-content/uploads/2017/06/EBC_white_policy_paper_DEF26072017_Low.pdf

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.

Steiner TJ, Stovner LJ, Katsarava Z, et al. The impact of headache in Europe: Principal results of the Eurolight project. J Headache Pain. 2014;15:31. DOI: 10.1186/1129-2377-15-31

The All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD), Headache Disorders – not respected, not resourced. 2010. https://www.migrainetrust.org/wp-content/uploads/2015/12/2010Mar-APPGPHD_REPORT_Headache_Disorders-NotRespNotReso.pdf

Parikh SK, Young WB. Migraine: Stigma in Society. Curr Pain Headache Rep. 2019; 23(1):8. DOI: 10.1007/s11916-019-0743-7

Kostev K., Bohlken J., Jacob L., Association Between Migraine Headaches and Dementia in More than 7,400 Patients Followed in General Practices in the United Kingdom, J Alzheimers Dis. 2019;71(1):353-360. doi: 10.3233/JAD-190581.