

Shaping a pain-free future for cluster headache patients. The Declaration of Paris.

A publication to mark Cluster Headache Awareness Day 2018

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The members of the European Headache Alliance (EHA) Cluster Headache Special Interest Group (CHSIG), representing national non-profit groups in 10 European or European affiliated countries, have given their consideration to the management of cluster headache in Europe.

The CHSIG concludes that cluster headache management is inadequate throughout most of Europe for the following reasons:

- There is inadequate access to healthcare services for cluster headache (and other primary headache disorder) patients, and a failure to recognise that cluster headache is a serious, chronic neurological health problem requiring access to the kind of management available for other chronic diseases such as diabetes and multiple sclerosis.
- The knowledge of healthcare professionals regarding the mechanisms and management of cluster headache, and support for sufferers, is poor and needs to be improved.
- Cluster headache as a rare disease has a very low priority on the agenda of health authorities and researchers.
- Cluster headache patients are often stigmatised, labelled drug seekers or completely misdiagnosed.
- Most countries have inadequate national policies on the management and workplace protection of those who suffer from cluster headache.
- Patient associations supporting those who suffer from cluster headache are often not adequately consulted about the implementation of healthcare policy plans for cluster headache in their national territory.
- According to the European Headache Federation, more than 600,000 people in Europe live with cluster headache, with less than 50% of these patients consulting a specialist and more than a third missing work because of their condition, at a cost of 7bn euros per year.
- Cluster headache patients have poor access to accurate and reliable information about their pain and the available healthcare services for their disease.

- There are severe restrictions on the availability and affordability of effective symptomatic treatments and other therapeutic options critical to the management of cluster headache pain.
- There are unacceptable inequalities, across Europe, in the quality of healthcare assistance for this condition.

The 2010 Declaration of Montréal that Access to Pain Management is a Fundamental Human Right asserts:

- the right of all people to have access to pain management without discrimination
- the right of all people to acknowledgement of their pain and to be informed about how it can be managed and
- the right of all people to have access to appropriate assessment and treatment of pain by adequately trained healthcare professionals.

Accordingly, the CHSIG calls for cluster headache patients to be treated and managed in accordance with the above declaration. In order to promote these rights and shape a pain-free future for cluster headache patients, the group's members recognise the following priorities for action, at both European and national level:

1. To ensure that cluster headache, a rare but debilitating headache disorder, is formally recognised as a disabling condition and, furthermore, to ensure that national governments take into account that people affected by this condition often cannot work and require state support and assistance.
2. To ensure that spouses, partners and families of cluster headache patients are recognised as supporters and carers and are treated as such by their national governments, being offered the same level of support and assistance available to other carers or supporters.
3. To ensure that cluster headache patients have equal and easy access to high quality healthcare and social care, without borders, according to the standards, guidelines and best practice available for this condition, across the European Union and wider European Community.
In particular, abortive treatments such as high flow or ultra-high flow oxygen and sumatriptan injections should be available to all sufferers.
Patients should be guaranteed timely access to headache specialists.
4. To ensure that research into cluster headache

- pathogenesis, diagnosis and innovative treatment options is supported, improved and coordinated across the European Union and wider European community, and that patient organisation involvement is strengthened at every level of this research.
5. To ensure that appropriate strategies to enhance access to innovative treatments are put in place in the respective countries, and encourage the establishment of specialised centres for headache, which should work together, across borders, to improve the condition of cluster headache patients.
 6. To ensure that accurate and simple information is made available to patients, enabling those who endure cluster headache to make informed, factual choices according to their wishes.
 7. To ensure that patient feedback is listened to and acted upon and, where organisations representing cluster headache patients exist, that their advice and assistance is implemented so that patients receive adequate and appropriate healthcare.
 8. To ensure that awareness-raising initiatives on cluster headache and other primary headache disorders are promoted and encouraged.

The EHA Cluster Headache Special Interest Group urges the national governments of the EU and wider European community to agree to promote a pain-free future for cluster headache patients.