

In the face of pain there are no heroes. An open letter to the members of the European Parliament about ensuring in the whole Europe high quality care, research, equitable employment opportunities, and socio-economic support for Cluster Headache (CH) patients.



A publication to mark the Cluster Headache Day 2017

- Cluster headache (CH) is a quasi-rare excruciating form of primary headache, characterised by recurrent unilateral, short attacks of very severe headache, accompanied by autonomic symptoms/signs (i.e. rhinorrhea/nasal congestion, lacrimation, conjunctival injection) and restlessness. These attacks most commonly appear in clusters i.e. active periods separated by pain-free remission periods (1).
- **Cluster headache is arguably the most severe pain condition that afflicts humans.** Patients usually describe the pain as “having a red hot poker forced through my eye”, an “agony”, “a trip to hell you can’t control” and they report that the intensity is so extreme it is unlike anything they have ever experienced (2).
- Many CH patients endure repeated attacks, lasting up to three hours, every single day. The severity of pain has earned it the nickname “**suicide headache**” and a suicidal risk exists in this condition (in a recent survey 55% of CH patients reported suicidal thoughts) (3).
- Due to the extraordinary severity of pain **the personal burden related to CH** comprising unemployment (more than 1/3 of the chronic patients has lost their job !), psychiatric complaints, poor quality of life, socio-relational and familial restrictions **is enormous** (4) (about 60% of the patients reports an impact on their family life, the rate of divorce is higher among CH men than in the general population and CH women have less children than non affected women).
- Living with CH for the sufferers is a dramatic experience with pain as a “never-ending torture” stealing their life. **For CH patients “days are made of fear for pain” immersed in feelings of loneliness, impotence and frustration** (5).
- Despite the diagnosis of CH being very simple, and rapid and effective treatments for alleviating CH pain available, **CH is largely under-recognised and under-treated.** Only 20% of CH patients receives an accurate diagnosis at the initial presentation of symptoms and less than 2/5 of the patients are correctly diagnosed. Average diagnostic delay is of 5.3 years and this delay prevents the access to appropriate therapies. It has been estimated that 2/3 of patients never receive the correct treatment! (6).
- Mismanagement of CH extends beyond missing the diagnosis and the prescription of the right treatments. In most of the EU, effective treatments such as oxygen or sumatriptan injections are not reimbursed or are reimbursed with capitious restrictions (the International Headache Society have recently made an appeal to their members to put pressure on national health authorities to reimburse oxygen for CH in every country). In most of the EU, medico-legal protection for CH sufferers is not guaranteed, as well as fast access to a headache specialist without waiting list or any form of psychological support (7).
- Cluster headache patients experience a double drama; firstly the disease with its attacks of unbearable pain, secondly the difficulty in finding access to high quality medical care, emotional support, respect, acceptance or simply someone that understands how devastating this disease can be. **The life journey of CH patients is paved with a tragic feeling of loneliness, misunderstanding and mistrust** (5).
- Barriers to adequate care for CH are strictly connected to its low prevalence and to the historical inattention of the medical system toward pain disorders. Like other rare or infrequent disorders, CH is not widely known – apart from the few specialists working in this area, it does not receive attention in the curricula of the physician and has a very low priority in the agenda of health authorities and of researchers.
- **Most of the barriers preventing an appropriate care of CH sufferers may be overcome with a little organisational and cultural effort.** The European Headache Alliance and the European Headache Federation have launched the **Cluster Headache Day** with the intention to solicit the **Members of the European Parliaments’ help in pro-**

moting actions for improving the quality of life of CH patients. We have identified **four key action points:**

1. *The MEPs are called upon, in close cooperation with the Member States, to implement legislation that allow equal and easy access to effective care for cluster headache patients in the whole Europe (oxygen and sumatriptan injections should be available immediately, everywhere at an affordable price !)*
2. *The MEPs are called upon, in close cooperation with the Member States, to support Research into the development of innovative preventive and treatment options for CH and other pain conditions and to strengthen the patients' associations involvement at every stage of this research*
3. *The MEPs are called upon to implement EU legislation that will ensure equal access to employment for people affected by CH and other pain conditions and to work with the patients' associations and social partners to highlight successful workplace adjustments, reintegration or other forms of employment protection, and to promote the use of the European Social Fund for these actions*
4. *The MEPs are called upon to encourage the Member States to acknowledge that CH is a highly disabling disorder and to promote actions to improve the quality of health assistance, educate, eradicate stigma and raise awareness about this and other pain conditions.*

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