

AT LESSONS FROM THE EXPERT PATIENTS – *advices for the physicians to improve their care of Cluster Headache patients*

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Cluster headache (CH) is an excruciating form of primary headache characterized by recurrent unilateral, short lasting attacks of very severe headaches and most commonly appearing in clusters, that is active periods separated by pain-free remission periods.

Due to the extraordinary severity of pain the disability in this illness can be very severe, and suicidal risk exist in this patient population.

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 receive 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!

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.

As for other rare or infrequent disorders, a precious but untapped resource is represented by the **expert patients (EP)** defined as *those patient with a chronic disease whose knowledge and experience about it empowers him/her to play a part in its management, and whose advice the physician may seek to improve various processes in managing that particular disease*.

In this project we have collected a list of recommendations from EP for the physicians engaged in the CH management with the purpose to improve their ability in taking care of CH.

Eighty-three advices from 25 EP (SP, I, UK, NL, SWE) were available for a qualitative content analysis. 77% of the EP' advices could be grouped in 7 main recommendations reported in table 1 (with their graphical representation) and referred as the 7th Commandments..

These commendments have been used as a guide to propose pragmatic patient-centered changes in health care services dedicated to CH patients. The following actions were started:

- a) To encourage the national and international associations dedicated to the headaches to multiply the initiatives to educate the physicians about this disorder
- b) To call upon the EU parliament and the member states to remove the barriers to the access to effective treatments and 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
- c) To solicit headache specialists and expert patients to create balanced and easy to read educational leaflets

- d) To invite the headache specialists to establish a partnership with the patients association active in their country and to refer them their patients diagnosed with CH
- e) To encourage the physicians to create facilitated pathways to allow a quick access to the headache specialists and to dedicate a part of the visit time to talk with the patients' carer

Essential references

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Table 1. Patients educating doctors: the 7th Commandments.

What physicians must know of patient-centred care of Cluster Headache patients (illustrations from *Carmel Monteil Cervantes*)

	<p>Prescribe the correct medication (sumatriptan s.c. and oxygen) at the right dose and in the right quantities</p>
	<p>Consider few clinical clues to make the diagnosis: it is very simple! (and educate other doctors.....)</p>
	<p>Provide good information and be able to correct the misleading ones</p>
	<p>Take patient seriously and listen to him to recognize his sufferings and that CH is a valid medical disorder that can have a significant impact on the person and support him (care not cure)</p>
	<p>Be sensitive to the CH consequences on the patient's significant one and provide if necessary family and carer consultation</p>
	<p>Suggest patient to not conceal and to be active in a patients' support group</p>
	<p>Allow quick access for CH patients to headache specialists and be available if necessary</p>