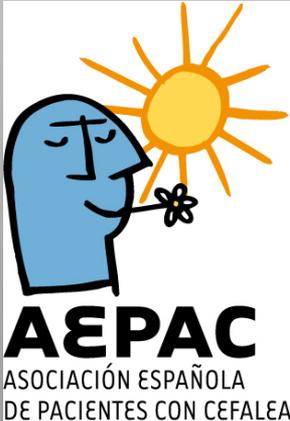




“Towards Active Patient Involvement in Healthcare”

**My Self-Management Experience**

Elena Ruiz de la Torre





# What is Migraine ?

Nobody dies because of a Migraine  
but it can be very disabling ...

- Migraine is a Neurological disorder.
- According to the WHO, a migraine attack is more disabling than quadriplegia or even being blind! (Menkel et al, 2000).
- Even though, it has been the most common neurological illness (affecting 12-15% of the population), it is often misdiagnosed, undiagnosed and/or wrongly treated in Europe.
- Migraine is the 12<sup>th</sup> leading cause of disability amongst women and 19<sup>th</sup> overall (expressed as years of healthy-life lost to disability - WHO 2001).
- In the European Union, every day, almost 600.000 people are absent from work or school because of migraine.
- About a third (34%) of migraine sufferers face difficulties or discrimination at work because of the headache. ( WHO, Factsheet 277, 2004).
- 3% of the migraine patients suffer more than 15 attacks per month. In Spain, that represents 1.600.000 people. (more than 16 football stadia!)

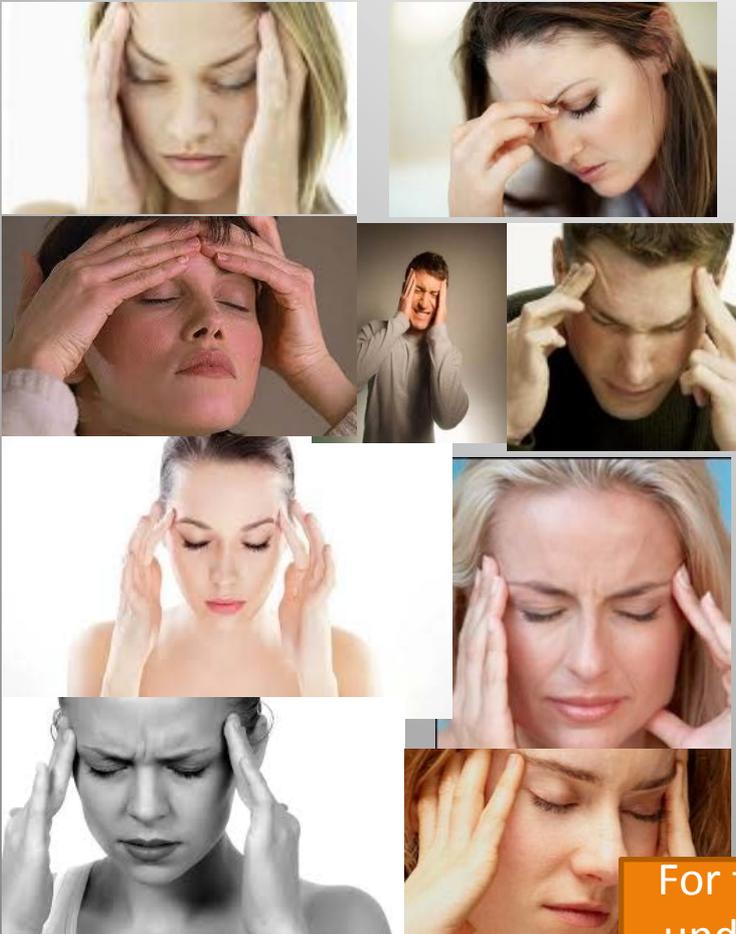


Dr. T.J. Steiner. EU Parliament 2006. EHA



# What really is a Migraine attack ?

What is wrongly shown in papers... :



Really, what happens when you suffer a severe attack – my experience :

- You cannot move or walk - you feel extremely tired, weak...
- You cannot even take the telephone to tell your office that you cannot go in until your medication works...
- You cannot open the eyes due to a high sensitivity to light
- You hear and smell 10 more times than usual
- You could have an uncontrolled attack of nausea and vomiting.
- You brain becomes slower.
- You have a huge palpitating headache in half of your head..
- And more .... !!!

For the Society, it is an act of faith to understand how awful migraine can make us feel.





# How has Migraine conditioned my life?

- I couldn't finish some of **my studies** at University because I had so many attacks.
- When I was 30, I had an opportunity for a very good **job** as Manager in an Official Governmental Institution. On the day of my interview, I couldn't leave my room... and they couldn't understand it. I missed out.
- Often, I was unable to go out with **boys** or friends conditioned by the pain.
- **Unable to drink** a glass of wine or beer at all.
- You learn to live without taking any promises to go anywhere or do anything because you know that you probably will not be able to. You often need to **excuse yourself and** this is even worse. (Big problem of social understanding).
- My life has always revolved around my migraine. All my decisions have been influenced by my situation.



I have spent all my life looking for a solution: going to the best Doctor, changing from one treatment to another, doing exactly what I was told to do, following the Doctors instructions.  
The result: My condition became chronic



# In 2005, I was proposed to create the Spanish Patients Group – AEPAC

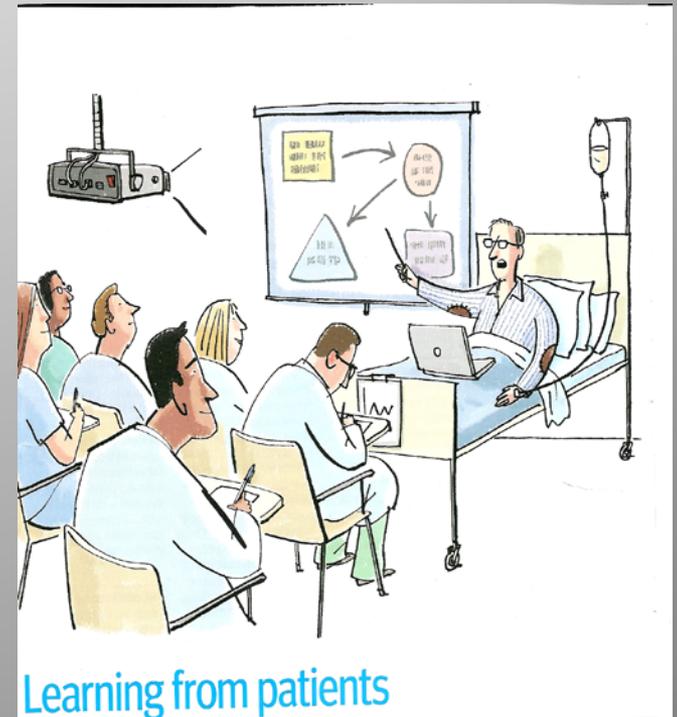


*And I left my personal company (at that time I was working for the America's Cup). And I have spent the last 8 years dedicated to advocating on behalf of migraine patients and AEPAC.*

## Why?

- Because I think we come to this world to leave it improved to the next generations,
- Because I think living with Migraine is highly frustrating and exasperating,
- Because I think there is a lack of support for patients,
- Because I think Patients can do a lot. Patients suffer, but also they know their symptoms, the treatment's side effects, they have a brain to work and to think.
- Because there wasn't any organisation for this illness in Spain.
- And because, very early, I met my colleagues of the European Headache Alliance and I understood the huge amount of things that could be done by the Patients Organizations.

Patients can be very active and productive





# MY APPROACH TO SELF-MANAGEMENT



- As we all know is no cure for a chronic disease, but there are many things to be done that we can do to improve our quality of life. I was inspired by my organization and the patients we supported.
- As a patient advocate, I needed to **educate** myself more about migraine and other headache disorders. **EDUCATION IS THE FIRST STEP TO SELF-MANAGEMENT. HEALTH LITERACY IS IMPORTANT.**
- I also **got to know more people** involved in this area from all stakeholder groups – including other patients. **PEER TO PEER SUPPORT (learning and support from other patients) IS ESSENTIAL.**
- I had an active approach and **positive personal attitude**. Nobody else was going to solve my situation. **A POSITIVE AND PROACTIVE APPROACH IS KEY.**
- I became involved as a volunteer in new clinical trials: neurosciences, **nutrition** and genetics **EFFECTIVE SELF-MANAGEMENT INVOLVES EMBRACING OTHER APPROACHES – NOT JUST MEDICATION E.G. NUTRITION**

And then, I started to improve in my chronic condition...!!

You need to take control of your own situation and to get there you need information and freedom.





# My Recommendations for Self-Management

- Patients need **to take control** of their situation.
- It is important **not to rely** on one Doctor or one treatment if it doesn't work. You should continue to search for more and more information or tools that work for you.
- Don't depend fully on health professionals and/or medications. Ensure that you always express yourself and your needs.
- **More information = More control.**
- Read Leaflets. Use **Patients Organizations.**
- Link with other patients.
- Use all tools available: Diaries, Social Media, Blogs,
- Explore new applications e.g. **MigrAPP** from AEPAC





# Example: A Self-Management Tool

We have more and more tools for monitoring our medication and our condition

# MIGRA-APP



“Creating a better world requires teamwork and collaboration between Policy-makers, Professionals, Science, Industry and **Patients**”.

## CONGRESO DE LOS DIPUTADOS



Conferencia Europea sobre Migraña, Cefalea  
y otros desórdenes neurológicos



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