

Epi-Log

Epilepsy - it can be a real headache, if you'll pardon the pun! On the brighter side, it also adds a whole new dimension to our lives. Epi-Log catalogues the good, the bad and the rarely-reported stories about a condition that affects 600,000 people in the UK - and rubs off on many more: their friends and family

Tuesday, 25 September 2012

Hello Hong Kong: may you continue to Enlighten all!

Really pleased to welcome on board, Enlighten - Action for epilepsy, a charity facing a hideous uphill struggle. Yes, I know all epilepsy charities have a hard time but listen to this....

Until relatively recently, the very word for epilepsy in Chinese (dean gan tsing) suggested craziness or madness cented on the character name 'dean'. Only in 2010 was the word changed to 'no gan tsing' disassociating the condition from the crazy character 'dean'.

Is it surprising then, with their society being so harsh that the 65,000 people in Hong Kong with epilepsy tend to squirrel themselves away, hiding their secret because they fear discrimination and social exclusion. Although...when Enlighten's communication officer contacted me, I wonder if she thought the UK was light years ahead. I don't think we're so very far ahead.

I think we've made a little more progress but - and here's the troubling bit - it seems to me mainly because lots of people in the UK now know what they're **supposed** to think or say about epilepsy. What many **feel** sadly hasn't changed much.

What has changed, is that there are many of us doing our own little bit to fight the discrimination and social exclusion that still exists - despite laws that are in place to prevent it. We're trying to enlighten people too.

I was talking to a young woman, 24, the other other day who said she found it hard to find work - even voluntary - and friends were few on the ground because her seizures (the full-performance tonic-clonic type) scared them off. That really hasn't been my experience but it's symptomatic of the fact, Hong Kong, that you aren't so far behind!

Another epi-friend pointed out that while most of us, in the UK, would imagine that there are no longer any issues facing members of other ethnic groups, members of other ethnic groups might tell the story differently.

While the subject of race has been heaved onto a public stage and debated at length, epilepsy which has been around as long, has stayed in the wings and has yet to make a real entrance anywhere in the world.

But we are definitely getting somewhere. It's people like those behind Enlighten that will make a difference to the lives of so many people who felt they had to hide away. Thank you for adding to the voice that's beginning to be heard.

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About Me



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I'm a journalist and have a form of epilepsy - but epilepsy doesn't have me in any form.

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