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Living with Epilepsy

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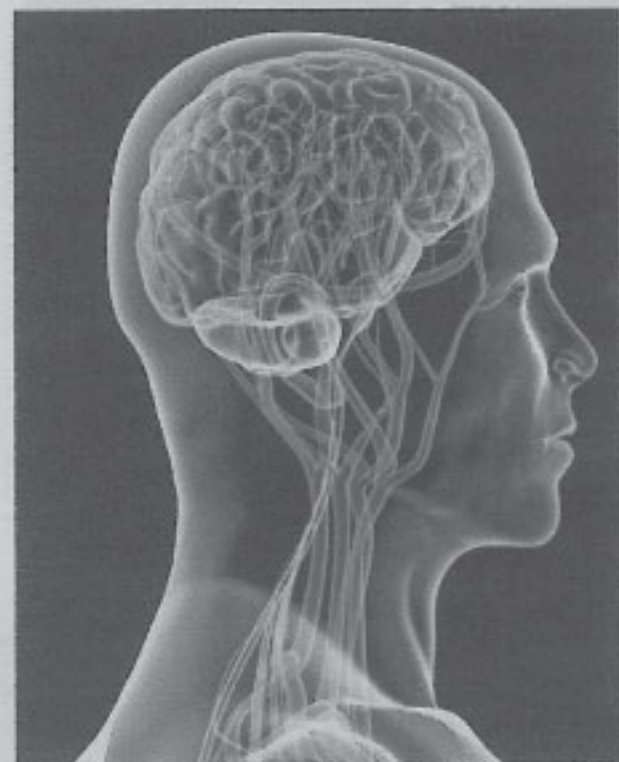
Epilepsy: Shaking off the

IN Hong Kong, 65,000 people have epilepsy, a brain condition that causes **periodic** seizures. However, what really makes life difficult for people with epilepsy is the condition's bad reputation. Because many Hongkongers misunderstand the nature of epilepsy, they wrongly believe that anyone with this disorder is cursed, crazy and incompetent. Heenu Nihalani presents the facts about this little-known yet significant social **stigma**.

THE brain has billions of nerve connections and sends messages to different parts of the body via the nerves. However, in people with epilepsy, these connections can sometimes get mixed up. This results in the body losing control and shaking **involuntarily** – this is called a seizure.

In most cases, a person with epilepsy cannot predict a seizure. Hence he or she must go about life knowing that a seizure could occur at any moment.

Numerous medicines, which prevent or reduce the number of seizures experienced by an epilepsy patient, are easily available in Hong Kong's public and private medical practices. However, there is no medication that can completely cure epilepsy.



Deep-rooted social stigma

Taking anti-epileptic drugs (AEDs) regularly and for the long term enables people with epilepsy to live normal lives. Yet even when their condition is kept under control with AEDs, people with epilepsy do get unfair treatment because of **prevailing misconceptions** about it.

An **erroneous** belief held by many Hong Kong people is that epilepsy is a curse on someone who has done something bad in the past. It is a commonly cited reason for badly treating a person with epilepsy. Others believe the disorder is contagious or can be passed on to children via pregnancy. The former is simply false and the latter has an extremely low likelihood of happening.

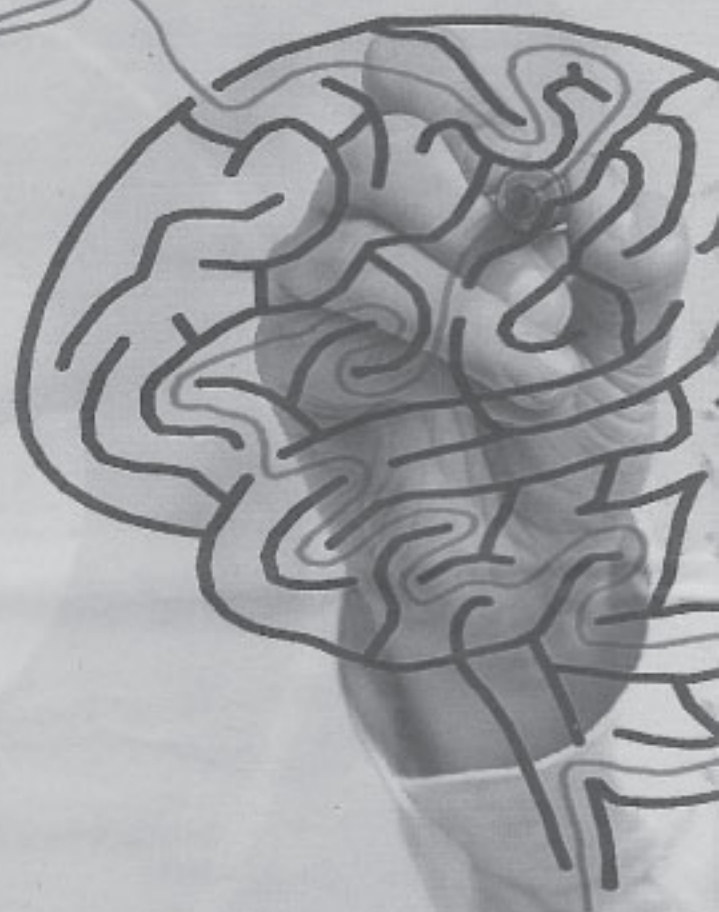
The Chinese translation of the word epilepsy does not help matters. In 癲癇症, the first character translates to 'crazy'. In a 2008 survey of people with epilepsy and their families, the results of which were reported in the *Hong Kong Medical Journal*, over 70 per cent felt that the Chinese name of epilepsy led others to think it was a mental illness. Only recently has the official translation been changed to 腦癇症, which has the more accurate meaning of 'brain seizure disorder'.

Perceptions of epilepsy in Hong Kong

- A survey of 1,128 Hong Kong people in 2002 revealed:
- 58.2 per cent had heard of epilepsy before.
 - 52.7 per cent of those who had heard of it said they would put an object into an epilepsy patient's mouth during a seizure.
 - 32.2 per cent would not let their children marry someone with epilepsy.



(Source: *Hong Kong Medical Diary*, 'Psycho-social Impact of Epilepsy and Issues of Stigma', Vol. 14, No. 5, May 2009)



Bringing epilepsy into the open

As a result of the stigma, "People feel ashamed of having the condition, and worry that they might have a seizure even in front of close friends and relatives," explained Claudia Schlesinger, CEO of Enlighten-Action for Epilepsy, a local support and awareness organisation.

"Many people living with epilepsy also find the condition shameful for them or even their family. Many children are told by their parents to keep their condition a secret," she continued. Indeed, more than 40 per cent of the respondents of the 2008 survey opted to hide the fact that they or their family member had epilepsy.

Stigma

Erica*, a 32-year-old with epilepsy, prefers to inform others of her condition, and many epilepsy organisations recommend this. At school or work, it is imperative that people know basic first aid skills to use when someone has a seizure.

Clearing misconceptions

These misconceptions lead to people with epilepsy being treated differently. During her 12 years with epilepsy, Erica has realised that, "A lot of people have a lack of understanding about epilepsy; this in turn may cause ill-treatment or fear when a seizure occurs."

For example, Schlesinger found that many people believe it is correct to put a spoon into someone's mouth during a seizure, to keep the tongue from being swallowed. "We tell them that it is totally wrong. This misconception is due to the media, as well as **preconceived notions** from our parents and grandparents." In fact, it is impossible to swallow your tongue during a seizure.

"There may also be **misinterpretation** of the capabilities of the person with epilepsy," Erica added. These misinterpretations are reflected in the 58 per cent unemployment rate among people with epilepsy in Hong Kong, a number estimated by social workers at Enlighten-Action for Epilepsy. Considering Hong Kong's three per cent unemployment rate, this is a shocking statistic.

People with epilepsy generally are no less competent, mentally or physically, than people without the condition. Yet Erica still feels that she needs to remind people of this. "I have to make extra efforts to prove that I can do it – sometimes better than others – because people think that those with epilepsy might not be capable," she said.

Having a seizure

"I faint, my hands and legs twitch. I feel very tired afterwards. But everything returns to normal after I have taken enough rest." – Erica

*Name has been changed to protect privacy.

More information

Enlighten-Action for Epilepsy www.enlightenhk.org
(in English and Chinese)
Hong Kong Epilepsy Association www.hkepilepsy.com
(in Chinese)



▲ People with epilepsy can – and do – lead normal, happy lives.

Looking ahead

The social stigma means that challenges for people with epilepsy extend beyond having seizures. Unfair treatment from people around them can be a daily test, although in cases like Erica's, her family and peers have been "more than accepting" of her condition.

More can be done for those with epilepsy. To that end, the social workers at Enlighten-Action for Epilepsy feel it is particularly important to raise awareness in schools. The organisation's free training programmes for students are a bid to chip away at the stigma, by teaching basic epilepsy knowledge and seizure first aid skills.

Schlesinger explained, "By educating [students] with the facts about the condition, they can play a greater role in removing the stigma associated with epilepsy."

GLOSSARY

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|-----------------------------|-------------------------------|-------------------------------|
| 1. periodic (adj. 週期性的) | 5. prevailing (adj. 普遍的) | 9. notion (n. 見解) |
| 2. stigma (n. 污名) | 6. misconception (n. 誤解) | 10. misinterpretation (n. 誤解) |
| 3. via (prep. 經由) | 7. erroneous (adj. 錯誤的) | |
| 4. involuntarily (adv. 本能地) | 8. preconceived (adj. 已先入為主的) | |