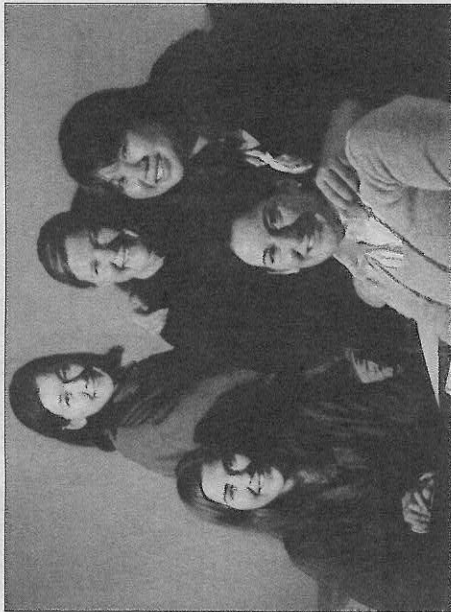


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Fighting the myths of the illness (left) are (left to right, top) epilepsy sufferer Melissa Webb, Louise Schumacher, whose son has the condition, and Enlighten's Stephanie Tang; (left to right, bottom) sufferer Laura Ferrington and Enlighten's Orta Gilroy; (above) parents whose children suffer from epilepsy enjoy a That kick-boxing bonding session organised by Enlighten. Photos: Sam Tsang

Don't shun us, try to understand and help, say epilepsy sufferers

John Carney
Miss Cheung did not want to give her first name or be photographed because of the stigma attached to her illness. Every so often she wiped away tears and struggled to find the right words.

It would have been easier to stop and walk away, but she was determined to tell the story of an illness that forced her to drop out of school and made it impossible for her to hold down a steady job; one that made her feel like an outcast in her own community.

The most devastating fact was that the illness Miss Cheung was battling her soul about was epilepsy – an illness not normally associated with this kind of heartache.

But in Hong Kong, people wrongly believe epilepsy is a mental illness when it is a neurological disorder. The Cantonese words *dir kan* refer to the illness which can mean crazy or insane, but superstitious thinking and a lack of awareness of the illness is prevalent in many countries. Sufferers here are often shunned and ostracised as Miss Cheung, 26, explained.

"At school I felt humiliated. Not just by students but by my teachers as

well," she said. "A teacher once put a steel spoon in my mouth in front of the class to show what to do if I had a seizure [research has shown this is the wrong thing to do if someone has a seizure and that nothing should be put in a person's mouth]."

"I was treated like someone who was crazy. Even my teachers tried to ignore me. In the end I left school at 15 years old with no qualifications."

It was only the start of a long and harrowing road. Miss Cheung was regularly fired from jobs because of her condition as it "affected the image of the firm," while colleagues would make fun of her. "I'd come to the end of my three-month probation period and be told I was not needed because of my seizures."

Once when she worked with a security firm, a work colleague sexually harassed her but when she reported it to the police they ignored it as her medical history showed she had regular seizures. "They thought I was mad so they did nothing."

Most shocking of all, Miss Cheung talked of how she'd often get seizures while walking in the street and pass out, only to regain consciousness as people walked by still ignoring her.

"It's been very, very hard but my

best friend suffers from epilepsy and we help each other. You need to have someone to talk to about it all because life can be so difficult."

For this reason the work of charity organisation Enlighten Action for Epilepsy has made a big difference to those who suffer from epilepsy in Hong Kong, and it is a sanctuary for the likes of Miss Cheung, who visits regularly.

They provide a welcoming environment at their offices on the 12th floor of Kwo Iwa Building, 340-342 Hennessy Road, Wan Chai, where people can meet and talk about what they are going through. Their main aim is to remove the myths that surround epilepsy.

Enlighten's chief executive officer, Orta Gilroy, said: "It's about educating people about epilepsy, and thankfully people are now not as afraid to ask for help when they need it."

To reinforce this, Enlighten is currently involved in Epilepsy Awareness Month, which includes a month-long education programme in schools to raise awareness of the illness.

Epilepsy is a taboo subject in Hong Kong to an extent. Children keep their condition a secret from

classmates while adult sufferers refuse to tell work colleagues because of widespread ignorance and prejudice towards the illness.

That's not just in Hong Kong either. Across the board, ignorance of the illness is widespread. What do any of us really know about epilepsy?

Epilepsy involves recurrent seizures caused by a malfunction of electrical currents in the brain. It occurs in one in 200 people and can affect an estimated one family in every 45 at any one time. It occurs in people of either sex, any race or age group, and affects people of all levels of intellectual ability. There are over 40 types of epilepsy.

Seizures can also have specific triggers for individuals like photosensitive epilepsy where sufferers have sensitivity to flickering or intermittent light stimulation such as watching television or playing computer games.

Enlighten helps parents come to terms with their child's illness, something that can be very distressing initially. Coping with the illness can be tough for parents, especially those with younger children. Josephine Mak wept as she talked about her seven-year-old son.

"It's the isolation I feel that is hard

to deal with," she said. "He is a normal boy despite his illness, but it's hard for him to understand this. I'm not crying because I'm sad, it's because it can be very frustrating at times."

For Laura Ferrington, talking about epilepsy is essential. "I've had seizures in the most bizarre places, like visiting factories for my work in southern Taiwan for instance," she said. "I couldn't do my job if I didn't tell people that I suffer from epilepsy. They have to know what can happen."

Ferrington could only imagine how awful it must be for someone to be out shopping with their best friend and constantly worrying about having a seizure because their friend did not know about their condition. Openness was the only way forward.

Everyone had different stories to tell about their epilepsy but they had one thing in common – they all praised the work that Enlighten was doing. None more so than Miss Cheung, who better than anyone knew it was a story worth telling, no matter how hard the task.

For more information or to make a donation to the charity, contact Enlighten on 28201111 or go to www.enlightenhk.org.