

SHE SAT NEXT to me in college, a student at a table we were sharing in the library. Suddenly, in the quiet, she started to groan. I watched in alarm as she began to shake. A teacher came along, moved books and pens out of the way to prevent her from hurting herself and let her get on with it. And as she quietened, the teacher gently comforted her.

It didn't last very long. Afterwards she looked pale and tired. "Oh God, I mean was it really embarrassing, did everyone look?" she asked. "No, don't worry," I said to reassure her. But I was shocked by the fact that had the teacher not stepped in, I wouldn't have had a clue what to do.

Epilepsy strikes one in 200 of us, irrespective of ethnicity or age. Although there are no official statistics, this means there are from 30,000 to 60,000 people with the condition in Hong Kong. It's caused by a malfunction of electrical currents in the brain, resulting in seizures. There are 40 types of epilepsy, the original Greek word meaning "the falling disease". Some are fairly mild, others can result in unconsciousness and even death.

While understanding of the condition is increasing and there's more medical and social support, misconceptions about epilepsy mean that sufferers not only have to put up with rare or common fits and the side effects of drugs they may have to take to control those fits, but also the stigma associated with something that many members of society know very little about.

"We emphasise that epilepsy is not contagious," says Orla Gilroy, executive director of the Hong Kong-based Enlighten Action for Epilepsy. "We recently trained some Filipino and Nepalese maids about epilepsy. One Nepalese girl was saying that back home her community believes that there must be an evil spirit in the sufferer, so they see it as something scary. They also pour water over the person's head to 'wash out' the demons.

"They would also put a shoe in the

person's mouth to stop the person having the fit swallowing their tongue."

Gilroy says she has to be tactful in her presentations and chats casually with people about the issues because there are hundreds of years of tradition behind views that are still widely believed.

She points to beliefs that you should put something in the person's mouth while he or she is having a seizure and also that if women eat mutton during pregnancy, it can bring on epilepsy in the child. Some people also believe that eating too much of the vegetable morning glory can bring on seizures. The superstition over sheep meat is so prevalent that the Society for Rehabilitation Community Rehabilitation Network website states that eating mutton during pregnancy has nothing to do with epilepsy.

But the stigma still remains. On parts of the mainland parents discourage their children from marrying people suffering from epilepsy. Until the 1970s, there was a law in Britain that people suffering from epilepsy couldn't marry. Sufferers also face prejudice in the job market and fear telling employers.

Stephanie Wong Suk-fong, a social worker at Enlighten, works with people who suffer from epilepsy and also visits hospitals to chat with parents of children who have the condition - if they'll let her.

"I see them pick up drugs for epilepsy from the pharmacy, so I approach them explaining where I'm from and the information we can provide and they sometimes just say that their child does not have epilepsy and walk away."

The stigma surrounding epilepsy is being broken down through the efforts of hard-working support groups. Annemarie Evans reports on their progress

Parents, concerned by the stigma attached, fail to tell teachers at school of their child's condition, says Wong.

As well as the problems, both Wong and Gilroy emphasise that thousands of people live with epilepsy and lead successful and happy existences.

"It's like diabetes, you take your medicine at a certain time of day," says Gilroy. "If you're going to the beach, you take it with you."

"I know a girl, she's in her early 20s," says Wong. "She's a kindergarten teacher and loves her job. She's had epilepsy since she was young and the seizures can't be fully controlled under medication. When she has a seizure at school, her colleagues know what to do.

"Her concern is that because she's just on a contract, senior management might

view the epilepsy negatively when it comes to contract renewal," the social worker says.

The strength of much of the medication prevents them from driving cars, limiting some employment opportunities.

Worldwide, famous people are coming out with the message: "I've got epilepsy and it's OK." American actor Danny Glover has it. So did Sir Isaac Newton, Vincent Van Gogh and Agatha Christie. Scottish rugby player Tom Smith, who was behind Enlighten's branch in Hong Kong, has the condition.

Enlighten Hong Kong Action for Epilepsy is a non-profit organisation and one of 12 causes supported by this year's Operation Santa Claus, which is co-organised by the *South China Morning Post* and RTHK. Supported by the Keswick Foundation, the organisation's funding finishes in July. Gilroy is keen to secure new support so that they can continue their work and raise awareness, something she's passionate about.

"If anyone wants to know more about epilepsy, please call," she says. "I'll go through any door to talk to people about it, to make them more aware and to train them to deal with it. I'm keen to go to schools, airlines, anywhere. If I can't answer your medical questions, I know doctors who can and will put them in touch."

Research on epilepsy is constantly being updated. There's a high-fat diet, for example, that has been found to reduce or stop seizures in one third of children under 12. But both the high-fat content and near-starvation aspects of the diet

mean it has to be very closely monitored by health professionals.

Another, albeit small-scale study in Canada, showed how domestic dogs were used to detect the early onset of a seizure. About 15 per cent of the dogs studied could anticipate the child's seizure before it occurred. Though a scientist quoted by *Neurology* magazine, did not emphasise the research was preliminary.

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The Hong Kong Epilepsy Association at G/F, Wang Lai Hse, Wang Tau Estate, Kowloon. Tel: 2794 3010; fax: 2794 4820; e-mail: hkea@hkepilepsy.org. Hotline: 8207 0207

A parents' group for children with epilepsy can be contacted through the Princess Margaret Hospital, Patient Resource Centre, G/F, Main Building, 2-10 Princess Margaret Hospital Rd, Lai Chi Kok, Kowloon. Tel: 2990 2000

Hong Kong Epilepsy Info-Net at www.hkepilepsy.com (in Chinese)

The Hong Kong Society for Rehabilitation Community Rehabilitation Network provides information on epilepsy support for sufferers and their families at www.rehabsociety.org.hk

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Orla Gilroy Action group director