

# HEALTH POST

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Illustration: Angela Ho

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# Seizing control

Many Hongkongers with this neurological disorder struggle to overcome social stigmas but these attitudes are changing, reports Wynn Chan

Carla Chan, a fresh-faced and bubbly 27-year-old, looks a picture of health. But she's just been discharged from hospital and has become such a regular there that all the doctors, nurses and other staff know her by name.

A recent decision by Chan (name changed for patient confidentiality reasons) to start a family is the reason for these frequent visits – not because of fertility issues, but due to epilepsy, a condition that has plagued her since birth. Her condition had been controlled well by taking anti-epileptic drugs, suffering from only one seizure a year at the most. But mindful that medications during pregnancy could affect the health of a foetus, Chan sought the help of her neurologist, who advised using a relatively new drug, Lamotrigine, which is thought to pose less of a risk to the developing foetus than older anti-epileptic medications.

However, since Chan started taking the drug about eight months ago, she has had weekly seizures. The one that landed her in the hospital this time happened on a road outside a department store in Causeway Bay; she fell and hit her head, resulting in injury.

What Chan goes through is more common than you might think. Enlighten – Action for Epilepsy, a local charity that aims to raise awareness of the condition and assist epilepsy sufferers, estimates that about 64,000 people in Hong Kong have the condition, or about nine per 1,000 people. The causes of epilepsy are known only in a minority of cases. Typically these involve some form of brain damage, such as injury, low oxygen during birth, tumours, infections such as meningitis, stroke, or abnormal levels of sodium or blood sugar. There may be genetic factors involved, but in up to 70 per cent of cases, no cause can be identified.

Epilepsy awareness remains low even though it's "the most common serious chronic neurological condition", according to researchers from the University of Hong Kong's department of medicine, who in 2008 conducted one of the few epidemiological studies of the condition in the territory. Because of this, sufferers are often stigmatised.

"I'm embarrassed about having to carry my medication in my bag. A lot of people, including my friends, don't really know about or understand epilepsy," says Chan, whose eldest sister, mother and maternal grandfather all suffer from the condition. "My boss was worried that I would have a fit, so I had to give up [the beautician job] that I loved." She says her seizures are often brought on by flashing lights, a lack of sleep or stress.

Laura Ferrington, 32, who was diagnosed with epilepsy at age 15, travels frequently in the region with

her job as a sourcing manager. Her colleagues in Hong Kong and abroad have been alerted of her condition so they won't be caught off guard if a seizure occurs, and they know what to do during and after the event. Thankfully, she has enjoyed tremendous support and understanding from her employers and colleagues.

But she notices that while her Western colleagues may ask her candidly about her condition, her local friends and colleagues tend not to mention it. She often wonders how people with epilepsy are truly perceived by the local population.

Epilepsy comes from the Greek word *epilambanein*, which means "to seize" or "to take hold of". It affects 50 million people worldwide, with at least 2.4 million new cases occurring each year, according to a World Health Organisation report last year. From its first documentation in around 4000BC to the present, myths and superstitions have surrounded epilepsy. Until last year, the Chinese medical term for the condition, when translated, meant "crazy seizure disorder".

Psychosocial studies in China, reported last year in an issue of the journal *Epilepsy and Behaviour*, have found the stigma is universal among people with epilepsy and affects around 89 per cent of individuals and about 76 per cent of their families, causing loss of face and diminished self-esteem. As a result, social communication, quality of life, education, employment, marriage and having children are severely affected in people with epilepsy.



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CARLA CHAN, EPILEPSY SUFFERER

A survey of public attitudes to epilepsy in Hong Kong reported in the journal *Epilepsia* in 2002 found that nearly one-third of the people interviewed reported that they would not allow their children to marry a person with epilepsy, and 25 per cent of employers said they would terminate the employment of a person with epilepsy.

Bullied and teased at primary school, Chan was forced to change from the popular morning sessions at school to afternoon classes. At secondary school, she was not

32%

The percentage of Hongkongers who would not allow their children to marry a person with epilepsy, according to a 2002 survey



# of epilepsy

allowed to participate in any physical activities after having a seizure during her first physical education lesson. "Sometimes I get a warning feeling [aura] before a seizure, I might notice a strange smell or a painting might move like a scene from a martial arts movie, or a table might float," says Chan, who married her childhood sweetheart last year. "I might cry out loud at the beginning of a seizure, my arms and legs will stiffen [tonic] and then they will jerk [clonic]. I'll fall down and when I come round I'll feel

confused, weak and tired. These seizures can last up to half an hour. At other times, I might just blank out and lose awareness for a second or two without any warning or after-effects."

Epileptic seizures are recurrent and random, triggered by abnormalities in the brain that cause a group of nerve cells in the cerebral cortex to become activated simultaneously, emitting sudden and excessive bursts of electrical energy. This causes a temporary disruption in the normal



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DR EDMUND WOO KIN-WAI, NEUROLOGIST

messaging between nerve cells in the brain.

A seizure's effect depends on the extent and location in the brain where this electrical hyperactivity occurs. When both sides of the brain are involved in synchronised discharges, this results in generalised seizures, which can be characterised by a loss of consciousness with muscle contractions and involuntary jerky movements (grand mal or tonic-clonic seizures), or a short period of loss of consciousness only (absences).

The other variety, called partial seizures, occur when abnormal electrical activities affect only part of the brain. Partial seizures consist of subjective experiences or involuntary motor activity, or both, with or without loss of consciousness.

"The risks of seizures include physical injuries, sudden unexpected death [Sudep], psychological disturbance ... depression is common, especially when the seizures are poorly controlled," neurologist Dr Edmund Woo Kin-wai says.

In two-thirds of cases, epilepsy is well-controlled with medication and sufferers experience no side effects. The other third, for whom medication does not work, could turn to surgery. The most common involves operating on the temporal lobe, the area of the brain behind the forehead between the ear and the eye, where most seizures originate. A study by University College London published in

*The Lancet* last month found that 63 per cent of patients were free of seizures two years after surgery (excluding simple partial seizures), 52 per cent after five years, and 47 per cent after 10 years.

When she had that seizure in the Causeway Bay, Chan recalls people pinching her arms and legs and slapping her to try and wake her up. "Every time I wake up at hospital, I cry," she says. "I don't want my husband, family or friends to know because I know they worry about me. I don't want their pity or sympathy, either, so I don't tell them."

She did, however, contact Stephanie Wong, a senior social worker at Enlighten, who first came to Chan's aid seven years ago.

During a dark period of her life when Chan lost her mother, she came across Enlighten's website. Answering Chan's initial e-mail for help, Wong at first supported and provided counselling via text messages and e-mails.

Since then, Wong has been a pillar of support for Chan and many others suffering from epilepsy, organising peer group learning and sharing sessions, providing counselling when needed, accompanying sufferers to neurologist appointments, and helping them understand the regimen of drugs.

Enlighten has helped Chan meet and share her experiences with people of the same age who are in a similar position, and it's helped her find hobbies that have filled the void left by losing her job. She remains upbeat and doesn't let epilepsy stop her living a normal life, though she's put aside her dreams of motherhood for the time being and is tapering off Lamotrigine.

Ferrington, too has never let epilepsy stop her doing anything she wanted to. She hopes, however, that people will lose their fear of the condition and the people who suffer from it. "Try to be understanding when people lose control during a seizure, and don't judge them for what they say and do," she says.

Enlighten's vision is exactly that: "to build a community that is accepting and understanding of those with epilepsy that enables them to lead vibrant and active lives in Hong Kong". Claudia Schlesinger, CEO and founder of Enlighten, says: "It's taken seven years for a sanction from Beijing to officially change the Chinese translation for epilepsy. Now the condition is translated as 'brain seizure disorder'. It's our mission to provide support and care to those affected by epilepsy and to remove prejudice through community education." [healthpost@scmp.com](mailto:healthpost@scmp.com)

Additional reporting by Eileen Aung-Thwin. For more information on epilepsy, visit [www.enlightenhk.org](http://www.enlightenhk.org) or call 2820 0111