

Epilepsy patients suffering in secret

As many as 100,000 people may have the illness, triple the official figure

Simon Parry

Tens of thousands of Hong Kong people with epilepsy are suffering in secret because of prejudice and the stigma surrounding the illness, says an under-threat support group.

Enlighten Hong Kong, which faces closure within two months unless it can secure more funding, believes as many as 100,000 people – one in 68 – may suffer from epilepsy, more than three times the official estimates.

However, many children keep their condition a secret from classmates while adult victims dare not tell work colleagues because of widespread ignorance and distaste towards the illness, the group says.

People wrongly believe epilepsy is a mental illness and a sign of madness when it is in fact a neurological disorder, Enlighten Hong Kong's executive director Orla Gilroy said. As a result, sufferers are often shunned or ridiculed.

There are also alarmingly common misconceptions about how to help people with epilepsy.

The extent of the illness was highlighted when the three-year-old charity held its first Epilepsy Awareness Week last month.

"According to figures from the World Health Organisation, there are around 30,000 sufferers of epilepsy in Hong Kong but we believe the real figure is dramatically differ-

ent and more like 100,000," said Ms Gilroy, who says her estimates are based on calculations by local medical experts.

As with asthma and diabetes, there is no outward sign of the condition, and many sufferers choose never to tell even close colleagues or classmates of their condition unless they witness a seizure.

Phone calls to the group as a result of the awareness week campaign – the first of its kind in Hong Kong – led it to believe that the problem is much more widespread in schools than had been acknowledged, Ms Gilroy said.

"We rang one school to say we wanted to do a training programme for the school and give the teachers and students the proper tools to deal with the situation and we were told by the school they didn't have anyone with epilepsy," she said.

"We knew for a fact there were two children with epilepsy in that school. Often the schools are not aware and that may be a choice by the parents because they don't want their children to have the burden or the stigma."

Enlighten Hong Kong hopes to conduct a survey in the new year to gauge the number of epilepsy sufferers in the city but is hampered by a lack of funds that threatens to close it down within two months.

"We have got enough money to stay open for a couple of months at the moment but that is all," Ms Gilroy said.

"It is incredible the difference that the group has made to the families. It makes a huge difference to their lives. Without us, there would be a lot of people who would be very much on their own with this illness."



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