

Hiding *in* Hong Kong

One local charity aims to encourage children with epilepsy to live open and fulfilling lives, and hopes to dispel common myths surrounding this misunderstood condition, writes *Katrina Shute*.

Hong Kong teenager Noddy Chui was nine years old when he experienced his first epileptic seizure. While sitting with his father doing homework, Noddy suddenly became very rigid, his lips turned blue and he appeared to blank out. After several minutes he came to, then fell exhausted to his desk. His worried parents immediately took him to the emergency ward, and following several tests they were given the news their son had epilepsy.

“I was very frightened, as I didn’t know anything about it, what it meant or how to deal with it,” says Noddy’s mum, Pina. “I really couldn’t sleep much after his diagnosis, terrified he would have a seizure in bed and we wouldn’t know.”

Even worse for Pina was her son’s initial reaction to the news. “Noddy said he felt like a useless boy, and he

became very anxious and started having nightmares about seizures,” says Pina. “He became scared as he didn’t know when the next one would happen.”

The fear factor

While fear and confusion might be a common reaction for parents and children after a diagnosis of epilepsy, it’s made worse in Hong Kong where many myths surround the condition. In fact, up until 2010, the Chinese character for epilepsy literally translated as “crazy”.

Claudia Schlesinger is the chief executive of local charity Enlighten – Action for Epilepsy. She says Enlighten’s mission is to provide support and remove prejudice through community education. “We really need to change long-held superstitions about epilepsy,” she says. “Many people believe it’s contagious and





that it's a curse handed down from previous generations, and sufferers should be locked up at home and not spoken about. Even though there are 70,000 people in Hong Kong living with this condition, it remains hidden and something to be ashamed of."

Many parents have a hard time accepting the diagnosis, making it almost impossible for the child to accept it, and creating problems with confidence and self-image. The charity says it's common for parents to forbid their children from informing others about their epilepsy, including friends, teachers and even relatives.

"This sends the worst message to the child that this is something they should be embarrassed about," says Claudia. "It's also very dangerous, as the child could have a seizure at school or with other family members who won't know how to handle it."

But this kind of reaction is understandable when you consider the lack of awareness within the community. Onlookers feel uncomfortable watching a child having a seizure, especially if it involves jerking limbs, rolling eyes and saliva coming from the child's mouth. Parents report the most common reaction from others is to get as far away as possible.

Because of this, many kids with epilepsy are forced to attend special schools for children with disabilities and some have been banned from joining sporting teams, or dumped from the team when their condition is revealed.

"Kids with epilepsy are just like any other kids, with the same intellectual and sporting abilities,"

says Claudia. "They should be allowed to attend normal school and as long as their seizures are controlled with medication, they should be allowed to play whatever sport they want to."

The charity points to several high-profile athletes with the condition, including Olympic cyclist Marion Clignet and Enlighten Hong Kong's founder-patron, international rugby player Tom Smith.

"Playing sport will actually benefit kids with epilepsy because it's a great way to keep the body healthy and reduce stress, which is one of the major triggers for seizures," says Claudia. "As long as the child's coach is aware of what could occur and how to respond, there should not be a problem."

Free to live

With support from charities like Enlighten and by educating herself with the facts, Noddy's mother realized a diagnosis of epilepsy didn't have to change her son's life.

While the first medication they tried caused weight gain and failed

THE FACTS ABOUT EPILEPSY

- **Epilepsy is a brain disorder not a mental disease, and is not contagious.**
- **One in 100 people have epilepsy, 50 million people worldwide.**
- **Epilepsy can start at any age and equally affects people of all races and gender.**
- **Exact causes are unknown, but some cases have been initiated by birth trauma, a head injury, serious illness with very high fever, or drug and alcohol abuse.**
- **There are 40 different types of epileptic seizures, ranging from mild episodes like blinking or staring for several seconds, to major seizures where the person will lose consciousness, collapse and rapidly jerk the arms and legs.**
- **A seizure is the result of abnormal and excessive discharges of nerve cells in the brain, likened to an internal electrical storm.**
- **Seizure triggers include stress, lack of sleep, hunger, over-excitement, video games and flashing lights.**
- **With appropriate treatment, 70 per cent of people with epilepsy will be seizure-free.**

to reduce his seizures, the second prescription has been very successful. Noddy went from suffering a cluster of seizures every couple of months to being seizure-free and no longer worrying when the next one might hit.

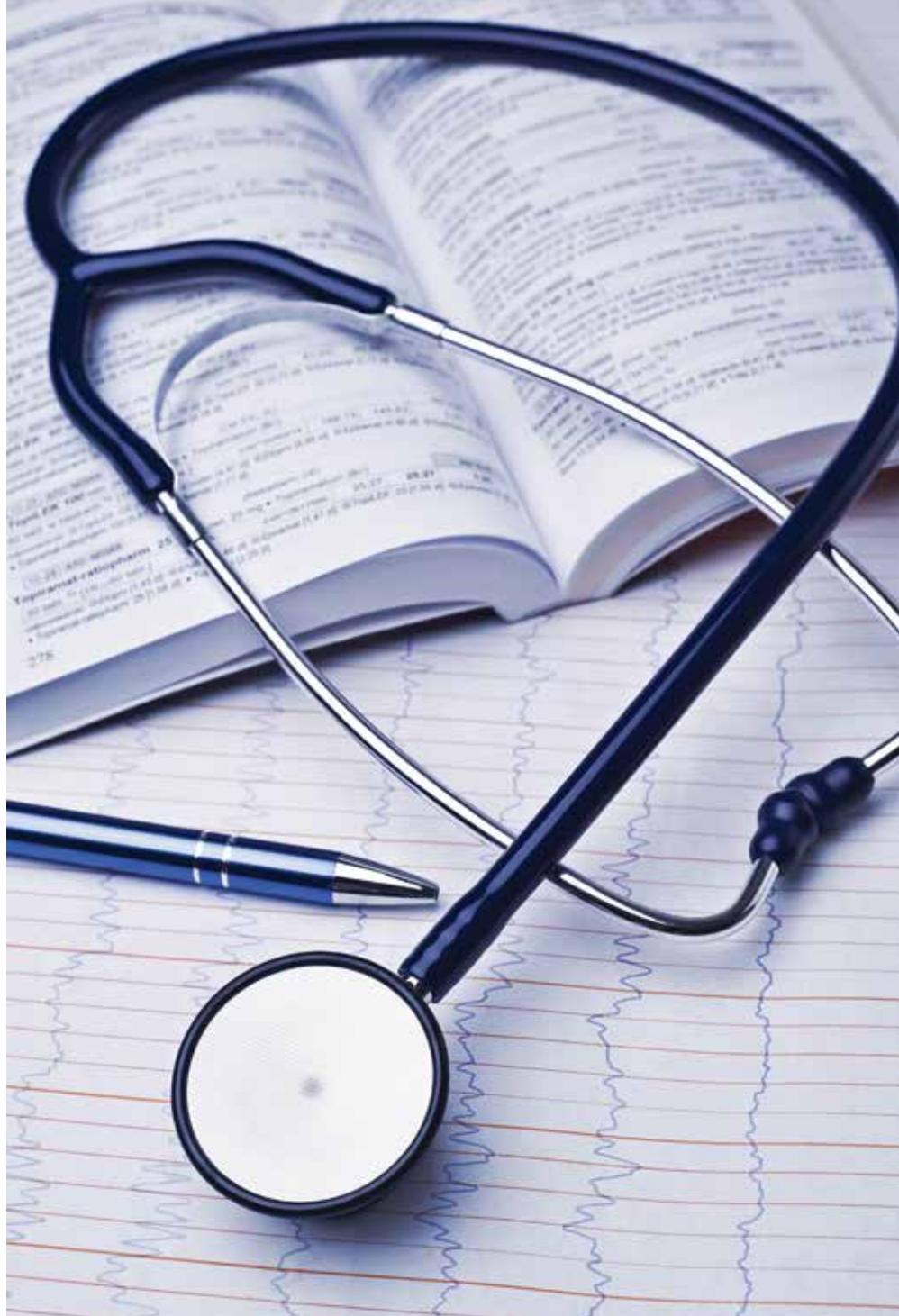
A talented bike rider from a young age, he gave up his passion for riding when first diagnosed, but returned to the sport when his epilepsy stabilized. He now participates in competitive BMX speed racing and trains twice a week. As long as he is wearing a protective helmet, he has his parents' full support.

"We don't know if Noddy will have another seizure, and we can't predict when that might occur, but we have to let him live the life he wants to live and enjoy the activities he enjoys," says Pina.

Currently 15 and attending a local school, Noddy excels at maths and economics and hopes to become an accountant. He is now able to self-manage his health by knowing what his triggers are, and offers this advice to other children who have epilepsy.

"Sleep earlier, get more rest and play less computer games because those will cause seizures," he says. "Don't worry too much and just enjoy your life." 🍌

Enlighten – Action for Epilepsy runs free epilepsy awareness talks and seizure first-aid training at schools all over Hong Kong. They can be contacted on 2820 0111.



HOW CAN YOU HELP?

If you encounter a child or adult having a seizure, follow this five-step seizure management plan.

- 1** Stay calm and make sure the person is safe.
- 2** Check the time the seizure began and stop people

crowding around the person.

- 3** Cushion the head and loosen tight clothing, particularly around the neck, but do not restrain the body or place anything in the mouth.
- 4** When the seizure stops, turn the person into the recovery position on their side.

5 Observe – they will either totally recover or the seizure will continue.

6 Call 999 if the seizure lasts longer than five minutes, if a second seizure occurs, or if the person is having difficulty breathing.