



The Cockroach Spirit of Ivy Soon

**WAR
WITH
EPILEPSY**

Good to know that you are concern about epilepsy friends!

We are delighted to walk along with people of dreams.

Bring kind deed through positivity.

Realize dreams through actions.

Fly high through perseverance!

— Words from Dream*ie*



Preface

Ivy Soon Chooi Yoke

Let The Love Flow

I intended to soothe my mind and soul through words thus started writing. Publishing a book was not in my plan. I was getting my scripts organized when I happened to chat with Siow Wei, an editor friend. When she found out that I was sorting out my stories on the conquering journey of epilepsy, she immediately invited me to post my stories in a column in the “Anak” magazine by JiaoZong. She wished that my stories could help promote “education on Epilepsy”.

I boldly accepted the mission though I had no experience in writing columns. After reading my first draft, Siow Wei excitedly persuaded me to carefully organize my content, then maybe one day we can publish a book. I just took a laugh at the thought as that seemed to be a far to reach reality.

Friends who subscribed to “Anak” magazine based on my recommendation all liked my stories. They were affirmative of my “cockroach spirit” and supported the idea to educate the public on epilepsy. My former teacher was eagerly looking forward to the bi-monthly magazine, waiting to read the last episode of my story!

The dream of publishing a book seemed to draw closer and closer. Yet, sometimes I burst the thought bubbles myself, as I felt that this dream was still far away.

The dreams of promoting public awareness on epilepsy or publishing a book were not in my life plan. After my stories were being published

in the “Anak” magazine for over two years continuously, and under the encouragements of Siow Wei, I gradually had a clearer view of realizing these dreams.

Many times, I shed tears looking back on my past. I decided to turn my grief into strength. I wanted to promote epilepsy awareness among the mass public through stories of my life. I do not wish others to suffer as I did.

To make the impossible possible, I started on my fundraising, strategic planning with Siow Wei, publicizing through Facebook, collaborating with bookstores on organizing events...doing whatever I could within my limits.

I sincerely hope that my stories could influence others and that this book be a fair and peaceful platform for the comrades with the same destiny. Then we can happily blend in with the society. I hope that this book helps in creating a more loving society and may the love of the public flow into our lives.

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My Shield - Protecting The Different Inner Me

Who would be sorry for my epilepsy?

What makes a person tough?

Tumbling? Suffering?

After some time, a tough person might forget that he could also be vulnerable.

I am a living proof of one who became tough through numerous falls of life. Diagnosed with epilepsy, undergone a brain surgery, the hurting from intentional and unintentional unfriendly treatments. These experiences had made me tough over time.

After a while, I forgot that I could be vulnerable too.

Having Fun In Pain

From the disgusting looks and intimidated faces of the surrounding people had towards me, I started to realize that I was suffering from epilepsy. Destined to live with epilepsy, it had brought me countless ostracism, feeling unloved, and burdening others.

To survive under such conditions, I sought solace doing some little things. One of them was singing. I could mimic very well some of the singers singing the popular songs during my era growing up. I could even find joy when hospitalized. Imagining myself a VIP enjoying French cuisine as seen on television when my breakfast was being served in the hospital room!

Though the food in hospital was simple and tasted bland, I was always happy as they served either fruits or pudding in every meal.

To me, it would be a particularly nice day if I did not need to be on drip!

All my faults?

I was from a big family with many relatives. However, I had never had close relationships with my cousins, uncles, and aunties. All owing to my “best friend”, Mr. Epilepsy, which frightened them away. I was always the first person to be blamed if I were with the cousins and any of them had any wrongdoings. To avoid being blamed and criticized, mum had always refrained me from playing with them. Despite being refrained by mum and unwelcomed by cousins, I sneaked to their places occasionally.

There was once when I went to uncle’s house to watch television with my cousin sister, a spoon suddenly flew out from god knew where, hit me hard on my head! I was crying over the emerging pain, but my cousin sister said coldly, “Who made you come over (to our place)?”

When I got home, mum promptly helped me cleaned up the wound and started nagging for not listening to her advice on stop going to uncle’s place.

Playing Alone

Besides not being welcomed by cousins and relatives when I was only six years old, there were no cousins around my age whom I could play with. Thus, I started playing by myself.

The cushions on the sofa became my playmates. I built a castle with the cushions and slept in it. I stacked them high then knocked

in one way or the other being frightened and got panic in such situations.

When I slowly regained my consciousness and felt the oil in my mouth, I knew I lost it again!

“Can’t you just control yourself?! How many times have I told you to ease up and control yourself?” mum couldn’t help but expressed her frustrations.

I looked at her helplessly, thinking, I had tried my best; I had suppressed it twice!

I really wished that mum could trust me, just trust me once.

But I knew it would not make any difference even I told her so. I had been a “burden” in the family. As a “burden”, I should not feel, should not demand, should not even voice out when being bullied.

If I complained to mum, I would get it back from her, “Did I complain about taking care of you? Did I say anything about how people view me? Can’t you be a bit more tolerant to your siblings? I did not give up on you. What more do you want?”

“Mum, I didn’t ask for this disease!” This was a statement I had longed to say since I was 12. Yet, I held it back. I was not in the position to say it.

No complaints, no sadness, accept the disease, tolerate the siblings, appreciate the parents...I had internalized these thoughts which became a thick wall inside of me.

My family had suffered a lot because of me.

Sigh! I really wished that someone, or some God could tell me why I was born with such fate, and when would the sufferings be over.

**1 Da-Mei: the first younger sister (addressing in Mandarin)*

**2 feng you: traditional Chinese medicated oil*

The school principal advised me to be more generous. Then I might not be so bothered by discrimination, which could trigger my seizure. He promised to explain about my health conditions to the schoolmates. “This is not like AIDS!” he said.

Speechless With Inaccurate Messages

I was granted special treatment when I went back to school two days later. I was not required to attend the assembly at the hall and could remain in the classroom. I was looking forward to knowing how the principal explained to the schoolmates about my epilepsy.

When the classmates returned from the assembly, they looked at me strangely.

“The principal said you fell into the river because you are having health problems, not committing suicide?”

“The principal said you are “protected species” and we should not be bias against you.”

“We better not get close to her. We may get into trouble if anything happens to her.”

Oh no...what did the principal tell them?!

My days began to turn sourish. I felt like I was lying naked under the sun, being an open target for gossip.

Those who knew me better greeted when we met; to strangers, I was invisible. Some ran exaggeratedly while yelling, “Run! It is AIDS, don’t get infected!”

I was speechless during these embarrassing moments.

I was not a monster, my epilepsy would not bite, why did you treat me so?

*3 *Xiao Yi: mother's youngest sister (addressing in Mandarin)*



I Am Not Crazy

Despite typical Chinese thought that seeing psychiatrist was humiliating, mum accompanied me on my routine counseling sessions which lasted a year.

Though I could smile away the hostile behaviors of classmates, I still felt hurt. Despite being hurt, I disguised to be strong so that the teachers who cared about me would not worry.

Unfortunately, there were times I could not help but ran to the teacher's office to express my pains! Afternoon supervisor was the only person whom I could be myself with esteem.

She believed that if I were merciful and forgiving to the classmates who ostracised or prejudiced against me, they would one day be sorry for what they had done.

I normally returned to class feeling better after being comforted by teacher's great love.

Visit To Psychiatrist?

The teacher's words became a thick wall protecting myself.

Worrying that my dilemma would bring long term adverse impact on me, she asked one day, "Have you considered consulting a psychiatrist?"

I took her advice.

In the hospital, mum and I walked pass the psychiatry wards guarded with iron bars. "If you continue behaving like this, you will end up here. You need to let go of yourself!" she said.

"I'm not crazy! I don't want to be here!" I thought.

had arrived. We waited for dad to pick us home after mum settled the bill.

“How are you going home?” I asked Ying.

“I’ll take the bus. Don’t worry about me.”

Looking at the petite Ying, I took out all my money and gave to her.

“Don’t take the bus, take the taxi. It’s faster and it stops at your doorstep.” She finally accepted as I insisted.

Zhi went home with me. She took the medication and rested on the sofa while waiting for her dad to come pick her.

When Zhi’s dad arrived, he kept thanking me. “Thank you so much! You are great!”

I felt shy hearing his compliments!

Challenge Was A Gift

I was only a Form 2 student and managed to handle the emergency calmly. I thought I was quite unbelievable myself!

I had to give credit to my epilepsy for making the “unbelievable” possible! If not for the experiences gained from my seizures, I might not remain as calm when came to emergencies.

Everyone faces different challenges and tests.

I believed there would be a day I overcome my challenge - epilepsy, as I believed that “Life is Beautiful”!



Fight Until The End

I was worried that my friends would hang me up as they had always kept distance from me during the primary years.

When I was in Form 3, I wanted to organize an outing with primary school classmates. I took up the courage to call them individually. I walked to the public phone two blocks away from home bringing my contacts book and a handful of coins.

Each time a call went through, I began to worry that the receiver would hang me up. After all, they had always kept distance from me during the primary years. Fortunately, no one hung up on me. Obviously, I worried too much. The boys did not resist me; some girls even chatted with me. Maybe we had grown more mature!

Seemed like the relationships had a good change, I suggested we have an outing!

Believe In Self, Strive Bravely

Wye Ming was my best male friend at that time. We were in the same class in primary school and went to the same high school. He still looked out for me during high school and was the only male who did not turn away from me.

When he knew about my outing plan, he not only participated, but also earnestly helped me in organizing the event. The destination we decided on was a beach, near Wye Ming's grandmother's home.

As I was wholeheartedly planning for the event, mum said "NO", throwing cold water on my excitement! "You are not supposed to be

I might have developed strong surviving skills over the years, a hardy survivor like a cockroach. I told myself: everyone else could give up on me, but I would never give up on myself!

I organized some gatherings with friends while counting down to the “execution day”. We took many photos during those happy gatherings. On each photo, I wrote down names of all the friends in the photos, in case I forgot them after the surgery.

My guardian angel teacher accompanied and encouraged me; friends, knowing the risks and unknown outcome of my surgery, told me that I would get through this!

To ease the tensions among family and friends, I told myself, “Soon Chooi Yoke, you had survived many life and death moments, you could survive this too! This time you will create the miracle, don’t wait for the miracle to happen!”

I repeatedly encouraged myself and inspired friends around me with my version of “Chicken soup for souls”.

Over time, the belief rooted deep in me and it seemed real.

Soon Chooi Yoke, this time, you must create the miracle of life!

**5 ShengBei: two pieces of crescent moon shape of thin wood, a traditional Chinese divination method.*

Survived?

Vaguely in my dream, I saw the surgeon walked towards me with a surgeon's knife as big as a cleaver knife.

Oh dear! What was with the surgeon? Did he really need such a big knife for the surgery?!

Oh my God.... I got to run fast! But wait, I can't move, what's happening? I don't want to be chopped up! The surgeon is getting near...

“Soon Chooi Yoke, Soon Chooi Yoke, bangun lo. Kamu dengar saya cakap? Kamu sekarang dekat ICU, operation sudah habis. Kamu ingat nama kamu tak? Sekarang kamu dekat tempat mana?” (*Soon Chooi Yoke, Soon Chooi Yoke, wake up. Do you hear me? You are in ICU now. Your operation is over. Do you remember your name? Where are you now?*)

“Saya Soon Chooi Yoke.” (*I am Soon Chooi Yoke.*)

Didn't the nurse just call out my name? Yet asked if I knew my name. I thought that was quite funny.

“Saya kat hospital kan, ada operation pagi ni.” (*“I am at the hospital, right? Had an operation this morning.”*) I replied her accordingly.

“Bapa dengan mak kamu dekat luar, saya panggil mereka masuk ya.” (*“Your parents are outside; I'll get them in now.”*)

Vaguely, I saw the nurse walked out of ICU (Intensive Care Unit).

I hoped I was truly awakened this time.



Do You Remember Us?

Your surgery lasted 8 hours, it is 4pm now! Do you feel any discomfort?

“Chooi Yoke, Chooi Yoke, do you recognize me? Do you know where you are? Can you hear me?”

I had heard this anxious voice for 20 years. I slowly opened my eyes and saw mum standing beside my bed. She was calling my name and asking many questions.

In a soft feeble voice, I asked, “Mum, what time is it? How long was the surgery? Where’s dad?”

Fresh Memory of The Surgery

“Dad is waiting outside, I’ll get him in. Do you remember all of us? Do you remember who are you? Are you able to move your hands and feet? Do you hear me?”

“Yes, mum, I remember all. Where are the others? All outside? What is the time now?”

“Your surgery lasted 8 hours, it is 4pm now! Do you feel any discomfort?”

My eyes trailed mum heading out of ICU. Shortly, dad dashed to my front.

“Chooi Yoke, do you remember me? The surgery is over, everything is fine. Are you able to move your hands and feet freely?”

I lifted both my hands, and slightly moved my feet. I was feeling a little tired, and slight discomfort in breathing. Maybe the effect of