

LIGHT BOAT, THICK MOUNTAINS



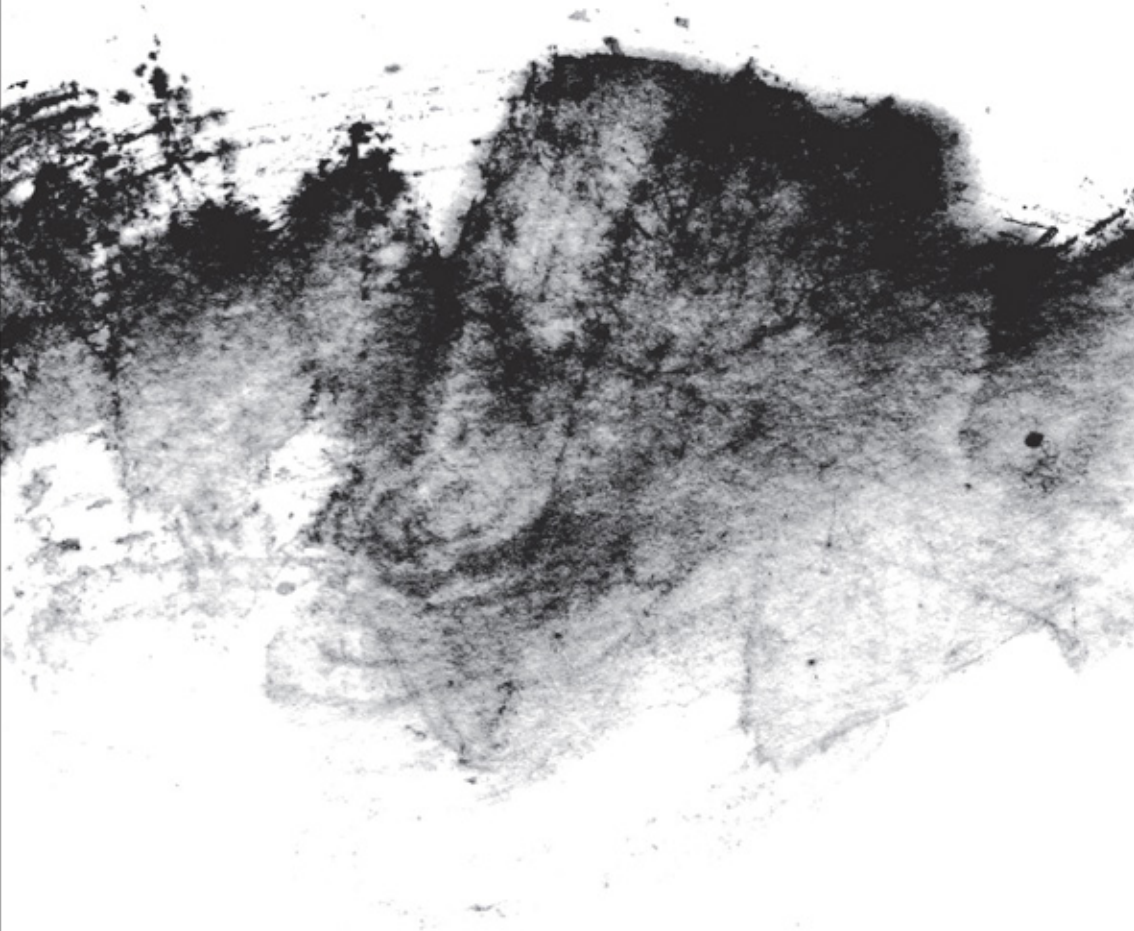
THE STORY OF
A POMPE DISEASE PATIENT

JOE LAI

LIGHT BOAT, THICK MOUNTAINS

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A POMPE DISEASE PATIENT





Book Title: Light Boat, Thick Mountains—The Story of a Pompe Disease Patient

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Photo source: shutterstock

Publisher: Riding Cultural and Creative Limited

Tel: (852) 9435 7207

Fax: (852) 3010 8434

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Distributor: Sup Publishing Logistics (HK) Limited

3/E, C & C Building, 36 Ting Lai Road, Tai Po, N.T., Hong Kong

Printer: Merrill IFN

Edition: 1st edition, April 2012

Price: HK\$68

ISBN 978-988-15914-4-9

Book Classification: (1) Popular Reading (2) Inspiration

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Published and Printed in Hong Kong

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FOREWORD BY LAU

AN UNPARALLELED LESSON ON LIFE

Joe's book is about to be published. He has invited me to write an introduction, and I, of course, am happy to oblige.

Joe always faces a “bellicose” question, which is: what is his “contribution” to society? It is a topic he and I often discussed. If we think of it in the materialistic sense, all our “contributions” are limited. Does it mean annual donations? That too is limited. Yet do money and possessions necessarily mean happiness and satisfaction? I said, “Joe, you can contribute something on the spiritual level.” Let me give an example.

Joe had once given a talk at a Lutheran elderly centre. In the audience were many elderlies who had their own problems. What was remarkable was that the elderlies appreciated Joe's efforts and his mom's perseverance in raising two boys with muscular dystrophy, and they were inspired by their stories (so was my daughter). What was even more remarkable was that the elderlies in turn encouraged Joe and his family. The incident showed that there is great love among us that can inspire and motivate. How can we say that is not a form of contribution?

In 1993, when I returned to Hong Kong from Canada, I thought deeply about my life's direction—Should I teach or pursue another profession? Back then, there were many cases of students committing suicide, and it prompted me to contemplate about life and education. Education meant education about life. I wanted to “contribute” a little in this area and so I stayed in the education profession. Then I met Joe, and he inspired me with his appreciation for “living”, his acceptance of “disease” and his perseverance (of course, he has the support of his all-giving mother). Joe has been living a colourful life and one that inspires others. Is this not his “contribution”?

As Joe's book went to print, I said to him, “Joe, this is your chance to give

back to society. Many people are going to be inspired by your book.” It is one life influencing another! I am honoured to see the birth of this book. When Joe sent me his manuscript asking for my comments, I suggested that he adopt a more systematic structure or make it a collection of essays. He was unsure whether he could do it in the beginning. But one of Joe's distinctive traits is his tenacity. He revised his manuscript over and over without complaint; not only seeking my advice but also forming an editorial committee with his friends Choi, Wong, Kong, Lee to edit and revise the manuscript. The dedication of Joe and his classmates was heartening. Ms Adeline Lai from the publisher also gave him constructive comments and selfless support. This shows that there is greater love among us.

This book is separated into two parts: The first is a collection of essays on Joe's upbringing and his reflections on life. The writing is impassioned, touching and inspiring. The chapter on Joe's brush with death was particularly illuminating about life's impermanence and Joe's vitality and will to survive.

The second part of the book is dedicated to the key characters in Joe's life, including his mother and brother, doctors, social workers and mentors and friends. The piece by his mother is the most touching. Mrs Lai leads us through Joe's life journey, from his birth till his muscular dystrophy.

The publication of this book will surely inspire our reflection on living and on life. It is going to be a very meaningful work.

**Associate Professor Grace Lau Yin-ping,
Department of Chinese, Lingnan University
Easter 2011**

FOREWORD BY TANG

A PHOENIX RISES FROM THE ASHES

A few months ago, I saw an American movie called *Extraordinary Measures* on TV. The movie was based on a true story about a father giving up his lush career for his children diagnosed with Pompe disease. He raises enormous funds to set up a research facility to develop the drugs, overcomes countless hurdles and finally finds a doctor to help him in his cause. The father and the doctor set up a pharmaceutical company together, and in the end successfully develop a drug called Myozyme to treat Pompe disease and save his children's lives.

Coincidentally, a month later, I came across the manuscript of this book by a Pompe disease patient. Joe Lai is now 26 years old. His disease onset was 13 years ago. Terry Lai, his 22-year-old brother, is also a Pompe disease patient. The book has two parts: the first chronicles Joe's disease onset and his quest for medical help; and the second comprises articles by Joe's mother, brother, teachers, classmates, social worker and physiotherapist, who share their views on Joe and the roles they play in his life.

Pompe disease is also called "Glycogen Storage Disease Type II". It is a rare genetic disease with two onset forms: the "infantile onset" form and "late onset". The disease is caused by the mutation of chromosome 17, rendering the body deficient of an enzyme to breakdown glycogen, a core substance that produces energy in the human body. The excess glycogen accumulated in the body will cause organ and tissue failure, affecting, most seriously, striated muscle and heart cells. Patients often suffer from muscular dystrophy and enlargement of the heart, and they usually die due to pulmonary failure.

The Lai brothers' Pompe disease belongs to the "late onset" form. Joe, after having the disease for 13 years, has lost his muscle strength and has only 5% of lung capacity left. He needs to be bound to a wheelchair and a respirator to sustain his life. His brother, Terry, who has had the disease for seven years, has a lung capacity of only 40%.

Since the medical community discovered the first case of Pompe disease in 1932, the disease has remained incurable. Most "infantile onset" patients never lived beyond their first year of life. In 2006, Professor Yuan-Tsong Chen, director of Taiwan's Academia Sinica's Institute of Biomedical Sciences, and his team successfully developed the drug Myozyme based on the principles of enzyme replacement therapy. This drug is highly effective on "infantile onset" patients. However, patients need to receive two injections each month for the rest of their lives, and the drugs can cost upwards of HK\$2 million each year. Infants with Pompe disease in Hong Kong can receive Myozyme treatment at public hospitals without having to shoulder the high medical fees. However, because the number of cases and the clinical evidence on the drug's efficacy on "late onset" patients remain scarce, "late onset" patients need to undergo stringent assessment before they are allowed to receive Myozyme treatment.

The Lai brothers belong to the "late onset" category. They have had the disease for years and their cells are already severely damaged. For that reason, they are not particularly optimistic about being approved for drug treatment. The chapter, The Case File of New Drug Applications, is about the medical assessment the brothers underwent.

Although I already know the results, I was still gripped by Joe's vivid account of the perturbation the brothers felt during the process. I worried for them. I clutched my fist and bit my lips as I read about their experience and the twists and turns of the story. This chapter shows how well Joe has mastered his portrayal of the incidents.

This book also shows the ugliness of humanity. For instance, in the first chapter, Joe talks about how some of his classmates ruthlessly judged him, mocked him and mimicked his gait after his disease onset. What upset him the most was how some of his female classmates "stabbed him in the back", jeering at him when he went to the bathroom and comparing him to a "turtle climbing the stairs". If it was not for Joe's report, I would never believe that there were students who would find pleasure in other people's disability.

Ban Gu, the poet from Eastern Han dynasty, said, "Education is to follow

the example of the leaders. Those at the top act, those underneath follow.” The principal of Joe’s school, even though he was fully aware that Joe was not physically capable of climbing stairs, acted as if nothing happened. He did not even ask the teachers to convey his concerns, nor devise ways to resolve Joe’s stair climbing predicament. Thus is an example of those underneath following those at the top.

Because of Joe’s disease, he had to seek medical help everywhere. Not only did he spend a lot of money, the treatment also weakened him further. One of the chapters talks about three conniving doctors: The first was a greedy “Miracle Healer of the Housing Estate” who only helped when money was offered. The second was a “Master Bone-setter” who sold widely available “instant Chinese medicine” as his own concoction at a profit. And the third was a “Hidden Miracle Healer” who cavalierly prescribed laxative for Joe’s “blood replacement” therapy. What these profiteering bad apples with little regard for others’ lives did was infuriating. I hope the authorities would use this book’s descriptions as clues to weed out these immoral individuals, so that they could no longer hurt patients that are already in dire conditions.

This book doesn’t just portray humanity’s dark side, it also illustrates humanity’s bright side. During Joe’s senior secondary school years, he met many caring classmates—some would offer to carry his books and homework when he needed to switch classrooms, and some would collect his homework and take notes for him when he was hospitalised. Principal Chan of the Queen’s College Old Boys’ Association Secondary School often asked after Joe’s health and school life and he genuinely cared for Joe’s well-being. And Principal Wong of the CCC Yenching College helped Joe purchase life-support equipment that saved his life, also allowing him to repeat Form 7 and writing a recommendation letter for him to a university. After learning that Lingnan University accepted Joe, Principal Wong even offered HK\$10,000 of her own money to Joe for him to buy new clothes. The kindness of the two principals let Joe realise there is greater love in the world and changed his “long-held perception” about principals; even giving “principal” a new, positive meaning.

Aside from giving me an understanding of this rare disease called Pompe

disease, this book has also prompted me to rethink whether our lives should be measured monetarily. Ever since primary school, teachers have told us that life is priceless, that it cannot be measured by money and that we ought to cherish it. Yet in today’s Hong Kong, a group of powerful people would still debate over this arcane subject at meetings when two seriously sick young men are in dire need for help. It is ridiculous. I sincerely hope that the members of the Hospital Authority’s Expert Panel would carefully read this book before they meet next year to process the Lai brothers’ application for drug treatment again.

**Chiu-kay Tang, Associate Professor,
School of Chinese, The University of Hong Kong**

SELF-INTRODUCTION

JOE LAI

This book has taken two years to finish. As the book goes to print, myriad emotions flood my mind. For me, writing this book has allowed me to review, reflect and ponder about the past 12 years; also to bring it to a conclusion. This book is my “growing up”, and I hope to share some stories of my daily life with you.

The name of the book is *Light Boat, Thick Mountains*. It was taken from the last two lines of Li Bai’s poem *Sailing Early from Baidi Town*: “The noisy chatter of apes from the shores followed us all the way. Our light boat has already skipped past thick mountains.” This is also my story.

Li Bai was a close acquaintance of Li Lin, Prince of Yong from the Tang dynasty. When Li Lin revolted and betrayed the Court, he was caught and punished. The incident also implicated the innocent Li Bai, who was punished as a rebel and banished to the impoverished village of Yelang. Here, Li Bai lived in hardship, darkness, dejection, with no hope for freedom. Yet when he was escorted to the town of Baidi, he received the amnesty of Emperor Suzong and was set free to return to normal life. He was naturally elated. So he wrote this poem to record his feelings (as a poet) at the time.

For me, what I went through in the past decade was similar to Li Bai’s experience. Though it was a disease that destroyed and tested me, the hardship we shared was similar. Fortunately, for both of us, the days of hardship passed at the snap of a finger; and we were able to live in the light again and continue our journey on a broader path. That’s why I named the book after the poem for the relevance.

When I was first diagnosed with the disease, the doctors told me it was an incurable disease, that my body would continue to deteriorate as I aged. At the time, treatment for this disease was only at the research stage, and there

was no drug treatment that could stabilise or palliate the patient’s conditions. For that reason, I never expected to improve or even recover, and I dared not make any long-term plans or considerations for fear that I could not follow through. So I lived “in the moment” and took things one step at a time. Even though my life could be short, I still wanted to equip myself and use my limited, however insignificant power to do something meaningful and not live an empty life. That is also why I insisted on continuing my education.

Yet after the darkness came dawn. In July 2010, I came across a trove of information on Pompe disease on the internet. I was surprised to find that there were drugs to palliate or even improve the symptoms. What was even more exciting was that I found there were patients already using this drug in Hong Kong, with good results. This was perhaps a divine gift of survival, giving me the hope to live on.

Although we faced many challenges and hurdles when I sought drug treatment from the authorities, the care and love given to us finally moved the Hospital Authority’s Expert Panel, which approved my drug treatment and that of my brother. I sincerely thank everyone for their support to both me and my brother! Now, I can live in the light again and plan for the longer term, to do something I never thought or dared to do. This has been a pleasant surprise.

I must thank Professor Grace Lau, who has continually encouraged and motivated me to write this book. Without her coordination and encouragement, I would never finish this 80,000-word “self-review”, to take stock of and review my journey in the past 12 years. I must also thank my “comrade-in-arms”, my schoolmates who devoted considerable time and effort to help me structure the book, guide my writing and proofread the book. My special thanks go to chief editor Choi, who has helped to edit and proofread the book; and editors Kong, Wong, Lee and Chan. If it wasn’t for your advice on writing, I would never have been able to complete the book on my own. So thank you all for your support and generous assistance!

I would also like to thank the teachers, my family (mother and brother),

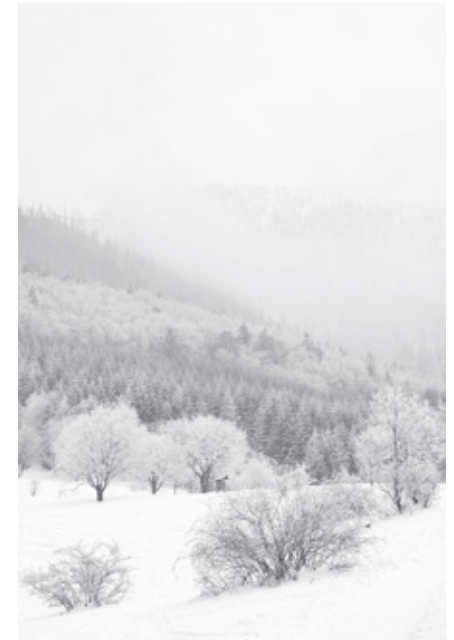
doctor, physiotherapist and social worker for taking time out of their busy schedules to help me complete this book. Much appreciated!

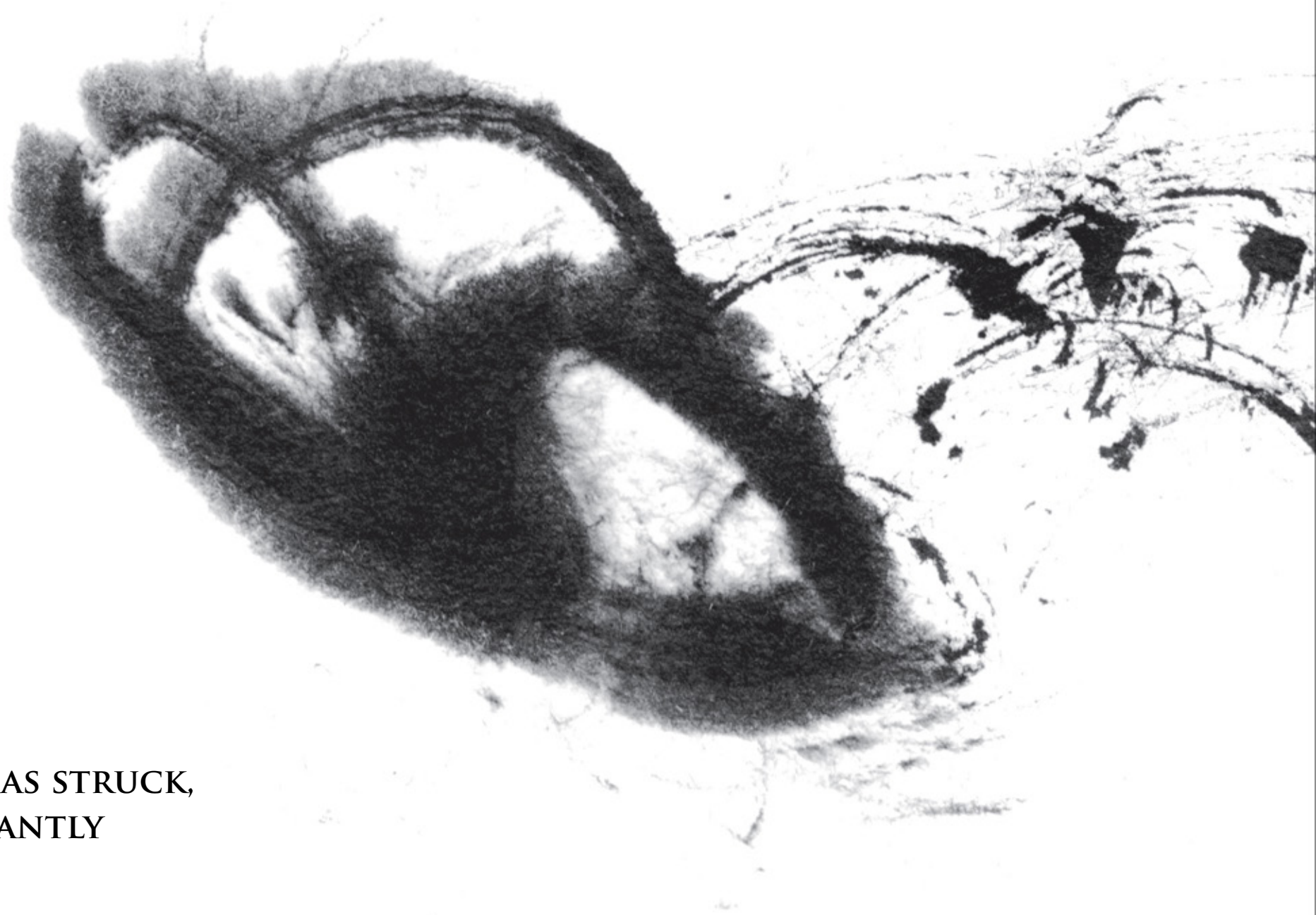
My gratitude also goes to editor Adeline Lai and publisher Riding Cultural and Creative Ltd., which handled the book's printing, promotion and distribution. Particularly Ms Lai, whose constructive advice on writing and pagination and whose work on fine-tuning, editing and proofreading the manuscript ensured the book's timely publication. I also want to thank the Arts Development Council (ADC) for its grant for publishing the book. Were it not for the ADC's generous sponsorship and support, this book may never have the chance to "see the light".

Lastly, I need to thank my parents. They have tirelessly taken care of me during the past 12 years—sometimes even having to put up with my temper—and will continue to do so in the countless days to come. As a son, I should have grown to be independent by now, have a career and repay my parents' love. Even if I can't repay my parents, I should at least be able to take care of myself and not remain a "burden" to my parents. I feel guilty about it! So, I dedicate this book to my parents, as a token of my appreciation.

Joe Lai

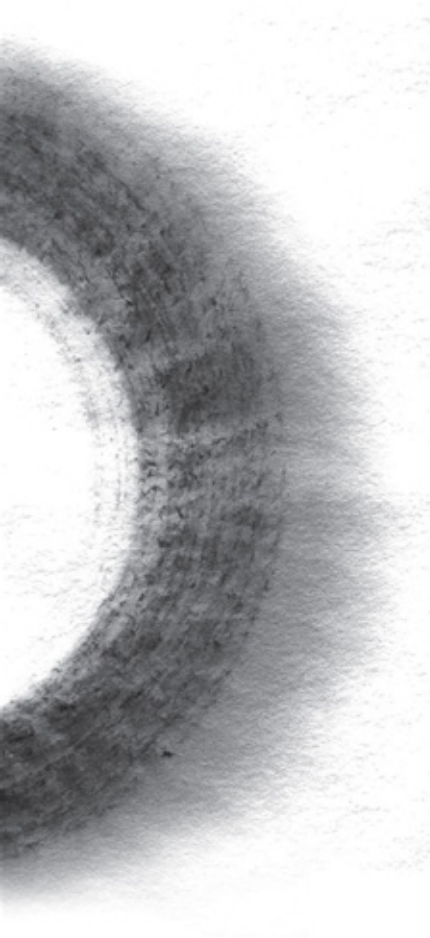
20 December 2011





PART 1

DISEASE HAS STRUCK,
DEFY VALIANTLY



CHAPTER 1

DISEASE, DISCOVERY, DILIGENCE— EARLY SECONDARY SCHOOL YEARS

SICK, MISTAKEN, WRONG?

I was a Form 2 student in the summer of 1999. The summer holidays had just started. For some reason, I had a fever and a diarrhoea that lasted a few days. Although I got better afterwards, I felt weak. When I climbed the stairs, I was like an old man—my back was arched, I had to hold the railing, and slowly pull myself up one step at a time. At first I thought this was the after-effect of the diarrhoea. I thought it would go away in a few days and so I didn't pay much attention. But it wasn't like that. The condition persisted for a dozen days. My mother began to worry, and took me to the clinic for an inspection. The doctor said I only had a hunched back and there was no problem. But my mother refused to believe, she knew there was something wrong with my body, only that the doctor couldn't detect it.

So my mom asked the head nurse who was on duty to assign another doctor to me, to ascertain that I was ok. After the preliminary inspection, the other doctor found that I indeed had strength problems, and recommended that I get a detailed examination at a hospital. But I thought I was ok, and firmly believed that I would regain my strength and recover after a while. I thought the hospitalisation was unmerited, that there was absolutely no need for it. Also, I had never been hospitalised in the past decade, and I didn't know what hospital wards were like, so I was greatly dissatisfied with the arrangement.

But the doctor said to me, "You are so young. Are you willing to remain like this your whole life? To not know what has happened, or find ways to regain your strength?"

I was certainly reluctant. But I could not convince my doctor or mother. So I unwillingly went to the hospital for a thorough examination.

I went through different tests at the hospital, including brain scans, sleep tests, taking muscle tissue and sending it to overseas labs for testing, etc. Doctors from different specialties also conducted detailed tests, evaluating

my strength, my gait, etc. The doctors' seriousness made me anxious and uneasy. I didn't know what was happening or what the disease was about. I was clueless and lost. And I was perturbed.

A month later, I went to the hospital for a check-up. The doctor confirmed that I had an unspecified disease that was later named Glycogen Storage Disease Type II, or Pompe disease. The cause of this congenital genetic disease was unknown, and there was no cure. The disease would cause progressive muscular dystrophy, I would lose my strength, my spine could curve, my heart and lung functions would gradually decline and I would have muscle fibrosis, with symptoms like that of muscular dystrophy patients. The difference was that the cause of my disease was different, and would eventually lead to death.

The news came like a bolt from the blue. I was devastated. I thought, "Why? Why would this happen to me?" I could not accept it, and I did not trust the doctor's words. I thought, "The doctor is lying to me!"

But as I walked each step with difficulty, I knew it was real and there was no denying. When I returned to school, I reluctantly told my head teacher about my condition, who in turn told the principal. That was the start of an agonising year.

That year, I got no sympathy from my classmates. I was lonely. One time, I ran into the principal when I reached the first floor. He saw that I was huffing and puffing, and came up to me and asked, "Student, are you ok? Do you need to go to the clinic?" I sensed that the principal didn't know about my condition, so there was no point explaining it to him. So I said I was ok in order to leave. But I realised the head teacher should have told him about my condition long ago, so why hadn't he approached me to check on my school life and make the necessary arrangements? I was bemused by how he was acting as if nothing happened.

For sure, I wasn't hoping for his special care, but he didn't even ask the teachers to convey his concerns. And he didn't even try to make stair climbing easier for me, such as assigning me to a classroom on the lower

floor (my classroom was on the third floor then). I had lost my trust in such a principal, and I wouldn't expect any special arrangements from him.

My parents, they had been running around looking for a cure for my unknown disease. Every day after school, they would take me to different Chinese doctors. Some treated me as if I had Rheumatoid Arthritis and others attempted an assortment of treatments. Such rash treatments made me even weaker, not to mention it was a waste of money. In just a year, we expended hundreds of thousands of dollars for nothing. Their medicines even caused repeated diarrhoea. I was physically weaker and spiritually drained.

By the time I returned home from the doctors, it would already be past 9pm. After eating and washing, it was almost 11pm when I could start to do my homework. And to have to finish a seemingly insurmountable amount of homework was very tiring. I often had to work till the morning hours before I could go to bed. Finishing homework was already a feat, not to mention preparing for class. Since I only had about six hours of sleep each night, I was constantly sleep deprived. There were always dark circles under my eyes and I would often doze off in class.

This same routine continued day after day, month after month. I was exhausted, I was physically and mentally drained. And my grades suffered. I slid from being 27th in my year when I was in Form 2, to being 91st. I knew it would happen, and did not mind it so long that my grades were enough for me to reach Form 4, that I wouldn't be eliminated. (There were some 200 students in my year. According to the school's regulations, 40 of the students would not be able to progress to Form 4 and had to be eliminated.) When the results of the final exams came out, I ranked in the hundreds but was still eligible for Form 4 in the same school. I was assigned to an arts class, which was fortunate.

On the other hand, since my disease onset and the doctor's referral, the Education Department was informed about my condition. The department's Special Education Section sent someone to visit me at my school during the

second term to understand my condition and discuss learning arrangements.

The department's staff inspected the school's environment and facilities. After their assessment, they decided the school was not suitable for me. The main reasons were that there was not a lift and that the school was located on a slope, which made access difficult. At the time, I had to get off the bus at the top of a mountain, and walk about a hundred steps downhill to reach the school. I would usually be out of breath by then. So they referred me to another secondary school to study Form 4, where there were people with experience caring for students with special learning needs. The Education Department called this "integrated education".

This new school had lifts and other facilities that could spare me from climbing stairs. I met the principal and the teachers and passed the written test. Just before the summer holidays, the school decided to take me in after a school meeting. I was ecstatic! When the Education Department's staff took me to my original school to withdraw, the principal's office was right next to the school office. When the staff went into the principal's room to inform him about my withdrawal, he still would not come out to speak with me, to ask about me or offer any caring words. His indifference broke my heart. After the paperwork was done, I left without hesitation.

But I actually missed the school. I had my fondest memories there, and it had motivated me to study. Yet I also had the most painful memories there. I withdrew to study at another school because of my disease, not because of any wrongdoing, and yet the school treated me coolly. So it can be said my attitude towards this school was a love-hate affair. But in any case, all these would soon be history, for not only did I have a new beginning in the new school, I met a group of principal, teachers and classmates that cared about me. They boosted my confidence and reignited my motivation to learn.

MY BUGGING SCHOOLMATES

The year I studied Form 3, my condition, particularly my bodily functions, deteriorated drastically. I was feeble from the hip down. When I walked, my legs felt like they weighed a ton. I would sweat profusely after just walking briefly. I climbed stairs like a 70- or 80-year-old man. No, I should say I was worse than a 70- or 80-year-old man. This was because I had to hold the railing with one hand while using the other to haul my legs up every step—bending my back almost 90 degrees. I was slow as a snail. Climbing 10 steps took three to five minutes. Because of that, I was often the butt of the joke of my classmates at my old school.

I still remember when school started and after the playground congregation ended, I had to climb three flights of stairs to reach my classroom. I was slow, but because I had to follow others to climb the stairs, I would often be the one who “broke up” the line with a gap of some 20 steps between me and the person in front. Sometimes, my impatient schoolmates behind me would overtake me to catch up with the students in front. Sometimes, certain curious classmates would walk beside me to “watch”, as if I was a show. They would comment on my walking and make fun of it. I was so uncomfortable I felt like there were thousands of fireflies around me. I would blush, but even more so, I felt ashamed. I wanted to be a groundhog and dig a hole to hide myself from their mockery.

Then, three schoolmates from another class came up, laughing at me and mocking my gait. They spoke to me. One said they liked meeting “peculiar” people, and teasingly asked why I would walk that way. Since then, the trio would often harass me and interfere with my life. And I couldn’t escape from their constant pestering.

From that day on, no matter I was climbing the stairs, resting, having lunch or leaving school, they would come up and bug me whenever they saw me. If I saw them from afar, I would “take flight”, like a mouse seeing a cat. Just that eight out of 10 times my escape failed. They would catch up and harass me. Sometimes I really wanted to fight them, but I knew I was powerless, so

I could only put up with their pestering. It was very perturbing.

After pondering for a long time, I came up with a dumb strategy, which was to stay in the classroom during recess so they couldn’t succeed in their ploy. At lunch, I would buy some noodles at the tuck shop or a meal box from lunch vendors and sit at the tables nearby and finish my lunch before 1pm. This was because Form 1 and 2 students had to eat in the classroom and leave the classroom before 1pm and rest at the playground. When they cleared the classrooms, the school’s two staircases would be locked until 1:25pm. That’s why I had to “climb” up to the library on the third floor before 1pm to hide from the trio, and rest in tranquillity for a while.

In the library, I would sometimes read newspapers in the Self-Study Room, or rest with my eyes closed. More often, however, I would feel sorry for my life and pity myself. I had a bright future before me, why did I contract such a nasty disease? I could not see the path before me, and I had no idea how the future would unfold. I didn’t know what to do or how to face the future. Whenever I thought about this, I felt unsettled and upset.

One time after lunch, the staircase was locked by the time I reached it. So I went to the large banyan tree opposite the playground and sat on the stone stools. As I closed my eyes to rest, the three schoolmates saw me and came over. They caught me just as I was leaving, and there was nowhere for me to hide. So I didn’t. I wouldn’t be a man if I did. I gathered my courage and said to them, “I don’t know you, I don’t even know your names. Why do you have to surround me and mess with me every time you see me?”

Surprisingly, one of them answered, “We like hanging out with peculiar people, and you are one such person.” Suddenly, I found that funny and maddening. I found that funny because they wouldn’t take a rest after lunch and prepare for afternoon’s class, but decide to come and mock me. What good does that do to them? Such naïve behaviour. If I was peculiar, I sure hoped I were someone who could fly freely in the sky and not be someone like me now, like a turtle that had to “crawl” up and down staircases. It wasn’t easy and I didn’t like it. I wasn’t qualified being called a “peculiar” person nor would I want such “accolade”. What was maddening was that their

pestering made me ashamed and embarrassed. It was a disturbance and an inconvenience, and I was angry about their behaviour. I wanted to swat them like a fly.

That said, they were already the better sort. At least they would do it explicitly and mock me to my face. I was troubled by their behaviour but not terribly bothered. What was worse were schoolmates who would do it behind my back. Like my female classmates who were usually quiet in class. I thought they would understand and empathise with me and not act like the trio in the other class. Little did I know, that was just my wishful thinking.

One time, I went to the third floor after lunch as usual. I went into the bathroom. As I took care of business, I heard these female classmates laughing uncontrollably outside. Their laughter echoed throughout the corridor. I didn't know what happened. As I listened carefully, I found they weren't laughing at some specific issues, but at my unusual walking—like a turtle climbing the stairs. When I emerged from the bathroom, they saw me and shut up.

They were, after all, my classmate for two years. That they would ridicule me like this, without the slightest regard of our fellowship, was outrageous. From that day on, I never wanted to speak with them again, or pay attention to them. I thought that way, I could protect myself from harm. I became a “folding chair” [closed up and set aside].

I tried sharing my condition with a classmate I was closer with. When I told him I had muscular dystrophy and my bodily functions would gradually decline, that I would lose my strength, that classmate seemed lost. He didn't understand nor did he say anything. The emptiness on his face made me realise he didn't know what it was about. I couldn't blame him. The term “muscular dystrophy” was unfamiliar to me either. I only knew very little about the symptoms. Not to mention my disease was Pompe disease, a rare disease, not muscular dystrophy. Their ignorance was understandable.

Now that I think about it, my shutting myself out and ignoring others were

utterly unwise. I thought I could protect myself, but that was not a solution. I was merely hiding from the problem and not escaping from the predicament. Everyone is curious, especially about something new; they are intrigued and want to explore. In that sense, their gawking was in fact normal.

If I looked at my own experience, if I saw an autistic person or someone acting strangely, I too would stare at them and observe their actions. It may be a reflex and not discrimination. That's why I no longer hold a grudge against the classmates who casted their bewildering glances at me, and I forgive them. But to those who intentionally ridiculed and disturbed me, I must say I still do not approve of their actions. There is an old saying, “Do not upon others what you don't wish upon yourself.” One should not derive joy out of other people's misery; because no one wants to be laughed at or treated rudely when one is sick.

RASH TREATMENTS

In the first or second year after my disease onset, my attending physician said my disease was a genetic disease that was still being studied by the medical research community. There were no drugs to palliate the symptoms to delay the deterioration of bodily functions and stabilise the disease. That was when my parents lost confidence in Western medicine and started seeking “famous doctors” to treat me. But these “famous doctors” treated me as if I had Rheumatoid Arthritis or Ankylosing Arthritis, and they attempted an assortment of treatments. Most of which were unorthodox. Not only were they unable to target my disease, these treatments weakened me further, both physically and spiritually. I did not even have the strength to walk. It was a waste of money, effort and time. Let me share two stories, to caution everyone against trying whatever is available during a critical disease or it may cause further damage.

MIRACLE HEALER OF THE HOUSING ESTATE

Since a doctor told me that the disease was Glycogen Storage Disease Type II, a relative kindly referred us to the “Miracle Healer of the Housing Estate” who lived in Yau Oi Estate in Tuen Mun. This relative told us that the doctor was the director of Chinese medicine at a hospital in Danshui in Guangdong, who specialised in neural injury and bone-setting, and that a friend quickly recovered from a sprain after seeing this doctor. So my parents took me all the way to Tuen Mun to meet this Chinese medicine practitioner.

After taking my pulse, this doctor applied moxibustion on my arms and legs and connected a machine to send electric currents through my meridians. She said this treatment, combined with the Chinese medicine she concocted, would speed up my recovery. She prescribed two doses, which comprised dried caterpillars and scorpions. I had never heard of or taken such “strong medicine”. It was indeed quite horrifying.

Seeing her picking these “special ingredients” sent chills up my spine, my hair stood up and I had a cold sweat. She said it was to fight poison with

poison. When I went home, I followed her advice with the hope of curing the disease. After decocting the medicine, I pinched my nose and gulped down the medicine, fearing to catch a whiff of the terrible smell.

I went on to see her twice or three times a week for treatment without interruption. For the consultation fee, she said we could give as much as we wished. So we handed her \$200 to \$400 each time. But we soon discovered that her attitude changed depending on the size of the fee.

We found that out because one time, after telling her about our economic condition and asking for understanding and a discount and giving her a \$200 red pocket, her face “darkened”, like a fabric burnt from ironing. At a repeat visit, we made an appointment for 6:30pm but found that she was not home when we arrived. We waited outside her apartment and tried calling her cell phone multiple times, only to be forwarded to her voicemail, and she never returned our call. By 9pm, I was furious. I didn’t want to wait any longer and demanded to go home. But my mother did not want to make the long journey for naught and asked for patience, for after all we were the ones seeking help. I reluctantly obeyed. By 9:30pm, the doctor and her husband casually returned.

Seeing that we waited patiently for such a long time, she let us in. During treatment, she explained the reason she went “missing”. She and her husband had gone to a banquet but could not return in time. She said she did not get our voicemail and apologised. We understood what she wanted to do, to use this chance to chase us away. When the treatment finished, my mother handed her \$400, and it was only then that the doctor grinned. She even chatted profusely as we were leaving, saying it seemed we had suddenly grown closer. I felt it was unfair, and we were wronged and helpless. I deeply felt how difficult it was to beg for help.

This doctor later recommended us to do a body check at her former hospital in Danshui, so that we could target treatment based on the report. We unwillingly agreed to her suggestion, and went with her to Danshui on a Saturday when I did not need to go to school.

On that journey, we had to pay for the doctor's and her husband's transportation and lunch. After we arrived at the hospital, she wanted me to do an X-ray and CT scan, and we obliged. These tests made me dizzy and weak. Because doing so many tests at once, I ingested a great dose of radiation and it was exhausting. Not to mention we spent a lot of money on the tests. When the report came out, it found that my forehead was shrinking and I lacked muscle strength. Yet she did not prescribe any medicine to treat these symptoms and her treatment changed nothing. This lasted another half year or so. Seeing that the treatment was not effective, we gave up going back for repeat visits.

MASTER BONE-SETTER

After some time, another relative told us about a "master bone-setter" in Tsim Sha Tsui, saying that this person was very good with bone injuries and constantly had a two-page advertisement in a newspaper; that she was a well-known physician. Because my scoliosis was worsening, my mother was excited to try after hearing the information. But I thought otherwise, reckoning it was a waste of money and time. Yet lacking better ideas or options, I complied to her wishes and went for a consultation.

Right after school one day, we went to the address on the newspaper. We checked in upon arriving at the clinic and waited for our turn in the lobby. After a while, a nurse summoned us into the treatment room. The moment I set foot in the consultation room, I felt it was not like a treatment room but a small exhibition hall. There were photos—probably dozens of them—of this doctor shaking hands with national leaders all over the walls. I did not understand the relevance between these photos and her medical skills, and yet these photos filled the room. I dared not ask the doctor, who sat across us with her husband.

When my mother told them that my disease was a genetic disease and not a normal bone injury, they insisted that mine was a spinal problem and not a genetic disease. So their treatment was to apply herbal paste dressing from my neck, my spine, down to my hips. I needed eight dressings and each was

charged separately. The first one was \$300, then \$100 for each additional one, for a total of \$1,000. In addition, they required that I receive a massage in the steam room and take Chinese medicine, for an additional \$500. All these services came to \$1,500. They claimed to sympathise that I was a student and offered a 20% discount, so the total was \$1,200. They even boasted effectiveness within two weeks.

I shivered. Why would a few pieces of herbal paste dressing cost so much? It was no joke even after the discount, and they called it a bargain! It was an astronomical number to me, and I had to continue for two weeks to see effectiveness. That must be a joke, and I thought we should just forget it! My parents' combined salary was only around \$20,000 a month. A two-week treatment would almost use up the whole month's salary. We would not be able to afford it if the treatment went on. I wanted to leave, but my parents insisted on the treatment. I had no choice but carry on.

During treatment, their so-called massage was just hitting my back with a backscratcher. There was no technique to speak of as they just randomly hit different places. What was even more ridiculous was that they completed it in just five minutes. It was very different from the "pressure points treatment" used by spinal doctors and it felt like child play.

What's more, their "prescription" drugs were just "instant Chinese medicine" available at supermarkets that were sold for \$20-30. It was not their homemade Chinese medicine and the efficacy was questionable. This shattered our confidence in the treatment. After continuing for three weeks without seeing an iota of progress, and that the doctor-couple could not confirm the treatment's effectiveness on me, we discussed and decided to stop returning as we could not afford the exorbitant treatment fees.

HIDDEN MIRACLE HEALER

After another some time, one TV station aired several episodes of a TV series called "In search of hidden miracle healers" about obscure medical treatments. One of the episodes was about an old person curing a patient

with muscular dystrophy using an alternative prescription, returning him to good health. My mother was excited about the news, and called the TV station asking how to find the old person, in the hope of asking him to treat my disease. Upon finding that this old person lived in a steel shack in Tai Hom Village in Diamond Hill, she wanted to take me to this “hidden miracle healer” right away.

But I had already lost all confidence in these so-called “miracle healers”. I was sick of their guarantees of full recovery. One time at the hospital, I overheard the conversation between a mother and her son that had an obscure disease. The mother was indifferent to “miracle healers”. When this mother first knew that Hong Kong’s hospitals were unable to treat her son, she resolutely sold her two properties in Hong Kong and used the money to take her son to the US for treatment. She hoped that overseas medical technologies could cure her son’s disease. Yet her high hopes were met with huge disappointments. She went around seeking famous doctors to treat her son, but even spending all her money her son was still paralysed without the slightest improvement. Dejected, they left the US and returned to Hong Kong. She advised my mother not to follow her footsteps and waste money on treatments of a disease that even the global medical community had no cure for. That seeking treatments everywhere would only result in disappointment, sadness, resentment, anger and confusion; in the end dwindling into a sea of misery and becoming more depressed, discouraged or even despaired.

But to hope and believe that miracle does happen is human. That, even against the greatest odds, it is always worth a try. My mother was the same. She begged and ordered me to see this Chinese doctor. At the time, I was already very weak, I had much difficulty walking and I frequently had to attend make-up classes that kept me in school from almost 7am to 5pm daily. By the time I got home, it was already 6pm. Schoolwork together with daily activities occupied 80% of my time, and I had little leisure time left. It was also a critical period at school as I had to start picking subjects for my senior secondary years. I should be focusing on my studies and yet my mother kept urging me to seek treatment; it was a headache for me. It was a headache because I barely had time for homework, not to mention the time

to study! I was very reluctant about seeking treatments also because I feared that it would be futile and bring only disappointment. But my mother kept coercing, and so I went to the doctors to quell her hope.

One day, we followed the doctor’s address and went to Tai Hom Village. We were not familiar with the house numbering and the location and so we knocked on different doors to ask. We found the doctor’s place after much difficulty. The doctor was slightly overweight, almost completely bald and seemingly in his sixties; but he had sharp, commanding eyes. We sat down beside his desk and looked around, there were all sorts of Chinese herbal medicine everywhere, from the steel racks to the floor; somewhat messy and disorganised.

After his inspection, he suggested “blood replacement” as the cure. We immediately questioned what he meant by “blood replacement”, for it was a confusing and scary term.

He explained, “What I mean by ‘blood replacement’ is that we will decoct the Chinese medicine I picked and you will drink and bathe in this medicine. The Chinese medicine will cause a diarrhoea and rid you of toxins, helping you to ‘replace your blood’. You will recover afterwards.”

Without skipping a beat, he handed me two big packs of Chinese herbal medicine, and urged my mother to decoct the medicine for me to drink and bathe. I was shocked by the sight of the two big packs, and I thought to myself, “You think I’m a cow, and want this cow to drink such a big pack of Chinese herbal medicine? Are you out of your mind?” As I was still perplexed about it, he explained, “This Chinese medicine can help you ‘replace the blood’, to rid your body of toxins and normalise your metabolism. Then you will be cured. I guarantee effectiveness in two months.” He tried to reassure me.

Still sceptical, I took the two big packs of Chinese herbal medicine, paid \$500 and left in silence. When we returned home, my mother followed his instructions and decocted one pack of herbs. But our clay pot was too small

for so many herbal medicines that my mother had to go to the hardware store to buy an extra-large stainless steel pot to barely contain all the herbs.

I drank a large bowlful of herbal medicine and felt sick shortly after. My stomach churned and swirled, and before long I had to go to the bathroom to “detoxify”. Yet after another 10 minutes or so, the stomach agitation returned, and I spent the whole day “detoxifying”. By rough estimates, I detoxified no fewer than a dozen times a day. I was exhausted like a leaky helium balloon—I kept falling and falling.

At my return visit, we asked the doctor to give us milder medicine, so that I could live normally. But the doctor was adamant about his prescription, and guaranteed that it was all part of the “blood replacement” process, that the diarrhoea was inevitable. When the “blood replacement” process completed, my bodily functions would recover and I could study, go to school and work normally. And so he repeated his previous prescription and again gave us two big packs of Chinese medicine for me to take home to drink and bathe.

Yet after taking these herbal medicines for about a month, I was weaker than before. I was drained of all energy. I could not concentrate on the teachers’ lectures in class nor in my studies. I just felt I was severely spent and wanted to just lie down and sleep. A thought occurred to me, “If this continued, I would be worn down before my ‘blood replacement’ is done. Wouldn’t that be terrible?” My mother was also frightened by the sight, and took the medicine to a nearby Chinese medicine store to ask about the ingredients. She found that there was a large amount of bitter gourd roots in the pack. The Chinese pharmacist said bitter gourd root was considered “cold” in Chinese medicine and would cause massive diarrhoea within a short period of time. It was usually prescribed for constipation patients to “un-constipate” and purge bodily waste. If it was used on people with loose bowels, the medicine would make the taker sluggish both physically and mentally, and cause difficulty in walking and breathing. The Chinese pharmacist advised using with caution.

Hearing what the Chinese pharmacist said, we asked the doctor frankly to

adjust the medication when we went for a revisit. Yet he still maintained that, “Having a diarrhoea is a good sign, it means that your body has started ‘blood replacement’. You will recover after the ‘blood replacement’ is complete. There is no need to worry.” Once again he gave me a pack of herbal medicine, but my confidence in him was mostly gone. I was sick of hearing the malarkey of “recovery” and wanted to tell him to stop the baloney and shut up! Just that to fulfil my mother’s wish I reluctantly continued taking the medicine. The outcome was obvious. After two months, my body could no longer bear the herbal medicines’ destruction and I was debilitated. Not only were the herbal medicines useless, my weight plunged in just two months. When my parents saw my haggard face and my even weaker body, they stopped forcing me to see this “miracle healer”.

At the time, I thought the “miracle healer” was a deceiving us like a swindler in a casino. They would set the bait to lure the willing and profit from medical fees. In fact, patients with muscular dystrophy are deficient of one or two enzymes, rendering their bodies incapable of getting enough nutrients and causing muscular dystrophy and malnutrition. Although the doctor was right in categorising “muscular dystrophy” as a metabolic disease, if simply using Chinese herbal medicine to induce “blood replacement” could resume normal metabolism, that would be delusional. That is because metabolic defects are a genetic problem. “Blood replacement” could only improve blood circulation but was completely irrelevant to metabolism; and definitely not the right treatment.

During my three-month treatment, we paid this person almost \$20,000 in medical fees. We found that the large pack of herbal medicine could be bought for dozens of dollars at Chinese medicine stores. That’s why I knew he was not some powerful “miracle healer”, just a fraud who knew a little about medicine and who was good at talking big.

I hope that my experience above would teach others to be calm when facing such incidents and think and analyse rationally before determining what to do and make cautious choices. Acting impulsively and recklessly would only cause blunders and deceit, harming oneself in the end.

I also urge other patients and families not to blindly look for so-called “miracle healers” or alternative treatments. Because the higher the hope, the bigger the potential disappointment. Not only that the patient may not improve or recover, it may make him/her even weaker and more pallid. The disease may even worsen and the treatment backfire, resulting in the opposite of what was intended. I must stress that I’m not against seeking medical help. I just hope that people would seek treatment with authorised organisations and from reputable doctors. I also hope that people would carefully weigh the pros and cons before deciding on the course of action. There is no point accepting reckless treatments just to hope for miracles to happen. You may end up hurting yourself or even making your friends and family pay a huge price. By then it would be too late for regrets.



SCHOOL TRIP VS SPIRITUAL JOURNEY

The last school trip I joined was in Form 2, when we went to the Tai Tong Lychee Garden. I had actually been to the Lychee Garden a few times before, but this was the scariest time.

The teacher who took us on the trip this time was our head teacher Mr Lee. When the other classmates were BBQ-ing and playing around, Mr Lee took the boys in the class on a special trip to the back mountains for a climbing adventure. Because we were all young and restless, everybody followed the teacher's suggestion. Though I was timid, I too succumbed to everyone's enthusiasm and wanted to get going.

Mr Lee took a dozen of us and we embarked on a mighty climb. We started on a mountain trail. As we reached midway, the trail started tapering, allowing only a single-file. We had to be careful with every step. By the time we reached the mountainside, I started to feel tired, so I stopped to take in the scenery.

I saw a canopy of green tree crowns (tree crowns are formed by tall trees, which is different from the shorter shrubs) swaying rhythmically and vivaciously in the wind, as if they were an ensemble of elegant dancers. It was so beautiful. But as I turned my gaze, underneath my feet was a steep cliff, so deep that I couldn't see the ground. It was a completely different sight from the scenery I saw just moments ago. Suddenly, I found myself standing on the ridge of the mountain, and I panicked, thinking to myself, "If I slip, I would plunge and I would be crushed!" I didn't know what to do and was petrified. My legs followed my instincts and I took two steps back, but I hit a sandstone wall. Boy, did it hurt! So I leaned against the sandstone wall and climbed slowly to the peak. After I reached the peak, I looked around, and found that the zoo we passed by earlier and the BBQ site were all under my feet. I was like an emperor surveying my kingdom below! On the other

side, I saw a panorama of mountain ranges, like a green ocean. We had to overcome hurdle after hurdle to marvel at such a view. I was ecstatic; I was not aware that my tiredness had already quietly dissipated.

When we came down, we looked for new targets. We found it after entering the forest behind the mountain. We entered the forest and followed a direction sign, we passed through the creeks, turned into a bamboo forest and continued as the sign instructed. Yet as we treaded on, we came back to the notice sign. We walked in a circle and came back to where we started! Everyone was a little scared as we may have lost our way. But just as we were panicking and agitated, Mr Lee said nonchalantly, "Since we're here, let's stay calm and work things out", to pacify us and calm us down.

After we cooled our heads, Mr Lee took this group of boys to a nearby area and we sat down for a picnic. When we were done, Mr Lee, with his calmness and wit, guided us out of the bamboo forest. As we stepped out of the bamboo forest, and out of our quandary, we all dropped to the ground, exhausted and unwilling to move ...

This trip turned out to be the last school-wide event I joined. My subsequent health issues prohibited me from going again. It was a pity.

I think Mr Lee had wanted us to go on the adventure to train our patience and perseverance, and to practice keeping a cool head even in an emergency, to not be frazzled when frightened. Perhaps he thought we were all pampered by our parents and lacked crisis management skills, so he wanted to use the trip to hone our adaptability.

I still remember his advice, "Since we're here, let's stay calm and work things out". Especially in sickness, whenever I was hospitalised and felt perturbed, I would think about Mr Lee, of how calm he was in the bamboo forest. His words have embedded in my

heart and moved my soul. It was as if he was telling me to focus on my recovery since I was already at the hospital. His words cooled my anguish and it was quite effective.



CHAPTER 2

FACT, REALITY, ENRICHMENT— SENIOR SECONDARY SCHOOL YEARS

BACK ON TRACK, REBUILD

SELF-CONFIDENCE

The year I studied Form 4, due to health reasons, the Education Department arranged for me to be transferred to another school that had experience caring for students with special learning needs and that had lifts. There, I continued my senior secondary school years. At the new school, I chose to continue studying in the arts stream. The principal, teachers and classmates had known about my condition and my mobility problems before I started, so they were prepared for this “distinctive” classmate.

NEW SCHOOL, NEW PEOPLE

I had met the principal and some of the teachers to discuss class arrangements before I was enrolled. So I was mentally prepared and was less anxious about the new school. Yet on my first day, my head teacher Ms Mak asked me to introduce myself in front of the class. When I looked at some 40 classmates focusing their gazes on me, I felt nervous. I was tense and I stuttered, and I stood there frozen. It was quite embarrassing.

Surprisingly, not only did the classmates not look at me differently, they welcomed me with a big, friendly round of applause, accepting me into their class. It was in such an amicable atmosphere that I began my new school life. Although, as a newcomer, I needed to adapt to the new school and the new people, I quite enjoyed the process. Not only did my classmates not ridicule me, they cared for me and supported me. I was touched! I spent a joyous year in this school and I felt that there was love. I regained my confidence with their encouragement and I was not afraid of talking about my problems. And I rekindled my motivation to learn.

Principal Chan would chat with me when he had time, asking how I was doing in health and in school. Sometimes when I passed by the school office and he saw me, he would come up to me and say some caring and

encouraging words. I had never had such an “endearing” principal before. The care and attention he showed was a little flattering and I never expected it. The teachers were also very nice and they looked after me. Especially my head teacher Ms Mak. Aside from asking if I needed any special assistance in class, she would also take me and other classmates to church and participate in the school’s Christian fellowship, listening to the pastor’s sermons and singing hymns. These activities helped to cheer me up. What’s more, the school assigned a tutor to me to understand and follow up on my learning needs. This tutor even referred me to her Chinese medicine practitioner when she knew I was going around seeking treatment.

My classmates were also very caring, particularly a few boys in my class. When I had problems with class and asked them for help, they would gladly answer my questions. They even showed me their tricks in handling some of the difficult questions (my maths was quite bad at the time and I was behind in class). They would explain in detail and illustrate on paper to help me follow their maths solutions and make it easier for me to understand and grasp the concepts. Sometimes I would just follow their methods. Occasionally, when I needed to take a leave of absence for repeat visits or hospital checks, they would collect my homework and take notes for me, so that I could quickly catch up when I returned.

As my limbs gradually lost strength, it became increasingly difficult for me to lift heavy objects (e.g. thick books, homework). But whenever we needed to switch classrooms, my classmates would offer to carry my books and exercises so that I could easily take the lift and meet them at the classroom floor. I was really touched by their generous help and support. I had never had so many people willing to devote their time to care about and understand my learning needs and help me look for solutions whenever I encountered difficulties. Under such an environment, I quickly acclimated to the new school life. I also regained my motivation to learn and my long-lost self-confidence.

Around this time, my scoliosis gradually worsened. My spine became S-shaped and part of it was even pressing against my right lung and affecting

my breathing. My gait became “unhuman” and I was constantly wobbly. Seeing this, the hospital’s prosthetists made a frame for my back for me to use at home and in school, with the aim of correcting my scoliosis. But in order to hold my spine in place, however, the frame had to be made with a sturdy material that was poor in air permeability. Going around school in an impermeable back frame during the hot summer was gruelling. I sweated profusely and my sweat rained. To make matters worse, symptoms of muscular dystrophy started developing. My body curled up and my body weight plunged. After wearing the frame for a while, my ribcage and hip were bruised red and black and became swollen. It lasted a few days and I was in excruciating pain. One day, I was no longer able to stand it. I went to the bathroom during recess, took off the frame and punched it a few times to let off some steam! Now that I think about it, it was such childish behaviour. Why couldn’t I even take that bit of pain!

DECIDING TO TAKE THE SCOLIOSIS CORRECTION SURGERY

As my spinal curvature reached 59 degrees, I became a big “S”. The normal back frame was no longer able to steady my spine. The doctors suggested scoliosis correction surgery, to prevent my spine from further pressing against my right lung and stopping my respiration. The doctor even warned that by the time the curvature reached 60 degrees, there would be no use for surgery and I could just await my destiny. So, in the summer between Form 4 and Form 5, I decided to have the surgery. After the surgery, I spent a week in the Intensive Care Unit before transferring back to the orthopaedic ward, where I awaited suture removal and my wounds to heal. After another month, I was transferred to a sanatorium for physiotherapy.

One day, as I was lying in bed resting, my teacher from the Chinese club (in which I was a member; I joined to learn about Chinese customs), my head teacher and a dozen schoolmates from class and the Chinese club came to visit and check on my condition. I was thoroughly moved! They had taken the trouble to come all the way from the New Territories—having to change transportation a few times—to the sanatorium on Hong Kong Island to see me. I was deeply touched by their kindness. I could not fight back my tears

and beads rolled down my cheeks. I'd never had teachers and classmates so compassionate that they would pray for me when I underwent surgery, wish for my surgical success and "climb mountains and hills" to visit me. This was something I never expected.

After two months, my condition improved and I checked out of hospital. I spent a further three months convalescing at home. After I recuperated, I returned to school to continue my studies. Just that having missed school for half a year, I was no longer able to catch up. By the time I went back to school, it was already time for the HKCEE exam. There was no way I could take the exams with my classmates. I could only part ways with them and separately head into our own futures.

ON THE VERGE OF LIFE AND DEATH

By 2001, my spine was already in an S-shape and the curvature reached 59 degrees. My upper spine was pressing against my right lung and it affected my lung contraction and respiration. So the doctors strongly suggested scoliosis correction surgery, for otherwise the scoliosis would severely affect my pulmonary function. That summer, I decided to take the surgery, which resulted in my having to twice fight for my survival.

THE FIRST BRUSH WITH DEATH

On the day of the surgery, I entered the operating theatre at around 8am. The nurses let me inhale some strawberry-flavoured anaesthetic and I was put out in under two minutes. They then began a major operation that was expected to last 10 hours.

When the operation started, the anaesthetist had to inject anaesthetics into the vein of my neck, enough to keep me asleep for a day and a night. It was done to lessen the pain I would have to endure, as the operation involved opening up my entire back, locating my spine, installing two L-shaped titanium rods to the sides of my spine, then puncturing each section of my spine with another wire and fastening the wire to the two titanium rods. The idea was to secure my spine so that it would no longer bend or shift. The surgery was like slicing a roasted piglet. If it was not for the anaesthetics, I would be in serious pain.

However, since my neck was curved to the right, the anaesthetist had mistakenly injected the anaesthetics into my aorta, which resulted in massive blood loss and the need for transfusion.

This error cost me over 4,000ml of blood. But the transfusion only replenished about 3,000ml, and I had to fight to survive. I still remember before I regained consciousness, I felt myself sprinting in a dark tunnel and I had to come out of the tunnel to wake up. When I did, my back was in immense pain; it was a piercing pain. I also felt that my lungs had

accumulated a lot of phlegm, which I could not cough it out no matter how hard I tried. I also had trouble breathing. The “two pains” were so severe that my eyes were tearing and my nose running at the same time. I also found out afterwards that the operation lasted longer than expected. It was after 12 hours that I was rolled out from the operating theatre.

When I was kept at the ICU, I was injected with morphine every four hours for pain relief. But with benefits always comes costs. Although the morphine did relieve the pain, it caused a massive phlegm build up in my lungs, making breathing difficult.

THE SECOND BRUSH WITH DEATH

Because of my condition, I had to rely on a respirator round-the-clock to assist my breathing, and to prevent phlegm accumulation in my throat that may lead to suffocation. But one morning, I was having serious trouble breathing, and the nurse kindly offered to perform sputum suction for me. I turned down her kind offer, but she would not relent, and insisted to remove my oxygen mask and perform sputum suction. The moment she removed my oxygen mask, I had difficulty breathing. I felt I was engulfed by fire and the burning sensation was unbearable. Instinctively, I fought back with my remaining strength, in the hope of escaping the sputum suction “destiny”. Yet she held down my arms with one hand and shoved a tube down my throat with the other. I exhausted my breath during the struggle and passed out.

While I lost consciousness, I dreamt about riding a bus without air conditioning (the kind people called “hotdog”). My younger brother, my cousin and I were in periodic costumes, with a fan in hand and a scarf, and we were playing Chinese chess. Holding a fan in one hand, I deftly moved the chess pieces across the chess board with my other hand, playing against the duo. As I was enjoying the game, the bus passed through the Tsing Yi North Bridge, and all of a sudden, I was in a vertigo. All the chess pieces swirled on the chess board and all of us wobbled, losing our balance. Everything went dark and I lost my bearings. I did not know where my brother and cousin went. Suddenly, a yellow light appeared afar. The light

was bright but not blinding. Seeing the light, I ran towards it without giving a second thought. I passed through the light and I woke up.

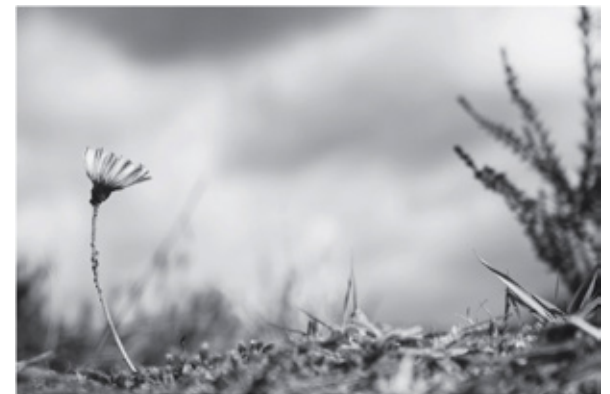
As I regained consciousness, I saw a dozen doctors and nurses surrounding me, staring at me. I did not know what was happening, only felt a sharp pain in my chest. I later found that my heart had stopped after I passed out and the doctors had to perform defibrillation to resuscitate me. My mother was in tears when I went under, and the head nurse was by her side consoling her, apologising for the other nurse.

After I awoke, my mother and I discussed whether to sue the nurse. I thought that since I was ok, we should forgive her and give her a second chance. Besides, I would be transferred back to the ordinary ward in a few days, we should not leave here on bad terms and cause embarrassment to all. So we decided to let it go.

That nurse transformed her behaviour afterwards, and was exceptionally nice to me. She seemed to have genuinely repented and I was glad to see that. A few days later, my condition stabilised and I was transferred back to the ordinary ward to convalescent.

THE PRECIOUSNESS OF LIFE

After these two incidents, I appreciated life even more, I also recognised how unwise I once was. For two years, I lived in self-pity and denial, I was despaired and depressed. I stopped communicating with others to protect myself, closing out the world. As a result, I wasted two years living in darkness and sadness. I need to treasure my God-given “rebirth” and do well in school, then I could do more meaningful work and live a full life with purpose and meaning. To not waste this life.



EVERYONE IS BORN WITH A PURPOSE

LIFE AT JFKC

After the surgery, I went for an interview at the Hong Kong Red Cross John F. Kennedy Centre (JFKC) at the referral of Mr Lo, the school's resident social worker. I joined the school as a transfer student and repeated the second term of Form 4 to prepare for the HKCEE the following year. This school was different from the normal grammar schools, in that it was a special school for students with physical disability, mobility problem or speech impediment. Students here were handicapped at different degrees, but they never gave up on themselves. Rather, they all strived to live the motto, "Everyone is born with a purpose".

After spending some time with them, I felt their positivity. They treasured every second of their lives and strived to do their best. Why did they work so hard? Because they all shared a wish: To give back to the society that had cared for them. That's why everyone worked hard. They dedicated themselves to their studies to equip themselves, with the aim of being able to find a place in society and support themselves and help others.

Although some of them were unable to move and had to rely on medical devices to breathe, they would still sit in their wheelchairs and focus on their studies. Their conscientiousness won my admiration. You see, they were not normal students, someone who could freely pick up a book to read or a pen to write. They had to rely on others to read, and when they needed to do homework, they had to control the mouse with their chin and type one character at a time. The physical and mental strength they had to use was unimaginable by outsiders like us. And the time and effort they invested in their studies must have been many times that of normal students. Their "making the impossible possible" opened my eyes.

Their formidable determination, tireless dedication to their dreams made me feel small. I can still remember how deeply I was moved and impressed

by their steadfastness. I thought, "They are so proactive in fighting for their dreams, why can't I?" I did not dare to slack here; I worked hard to prepare for the HKCEE so that I would not become a joke later.

In my class, I found that nobody studied Western history or Chinese literature. So I gave up Western history and studied geography instead. But because I did not study geography since I started senior secondary school and was only taking up the subject midway, I had to catch up in just six months, which was quite challenging. Fortunately, with the teacher's guidance I gradually caught up and became interested in this subject. As for Chinese literature, I really did not want to give it up. I loved Chinese literature. I thought understanding the poets' feelings and thoughts in their poems, feeling their happiness, anger, sadness and joy, learning about the many faces of society and the poets' worldview were helpful to forming my own value system. After expressing my wish to the teachers, they arranged for me to study alongside schoolmates in a lower form. But since their curriculum was not the same as the one for the HKCEE, I had to rely on the teachers to teach me the HKCEE-related chapters outside of class so that I could prepare for the exams. It was a makeshift arrangement indeed.

Not only that. In my old school, I took a class on Computer Studies. Here, the class was Information Technology. The curriculum was different, so I had to adapt and learn anew. That's why the year and a half I spent here preparing for the HKCEE was both busy and fulfilling. Academically, whenever I encountered problems, I could ask my classmates and schoolmates in the upper forms and they would gladly teach me. Especially when I asked them about maths, they would divulge tips to solve those equations, helping my grades in maths. My many interactions with them allowed us to understand one another better, which gradually built our camaraderie.

Life as a boarding student was memorable. Because boarding here was more than just dully studying and catching up on schoolwork. Sometimes, wardens, houseparents and the recreation staff would organise some extracurricular activities to spice up to our lives and relieve our pressure from studying. Indoor activities included singing contests, "big two" card

game competitions and food parties, which I particularly liked, as the houseparents would order grilled chickens and pizzas to indulge us and we could also get together and chit-chat. My favourite was seafood pizza. Whenever there was this type of pizza, I would need to eat two to three slices to satisfy my food craving and feel joy and satisfaction.

The annual “big wo” competition was a meeting of “masters”. Everybody used the opportunity to strut their stuff and earn the champion title. Was it not for this competition, I wouldn’t realise there were so many “hidden dragons”, people good at this card game, at school. I once entered the finals by luck and won the 1st runner-up.

As for outdoor activities, there were visits to museums, universities, and picnics. Activities that gave us exposure and an opportunity to get close to nature. During this year and a half of boarding, I even learnt about “healthkeeping”, such as effective breathing and nutritional products selection. My boarding life was indeed quite colourful.

Yet happy times passed quickly and HKCEE was soon around the corner. But I contracted pneumonia. I had a fever and my body boiled. I felt phlegm accumulated in my lungs and affected my breathing to the point of suffocation. The school’s resident nurse sent me to the hospital nearby for treatment. After admission, the doctors said I had to stay to clear the phlegm and do sputum suction. I slept dizzily at the hospital, and for a while I had low energy, which ended up costing me a month-long stay. I couldn’t attend classes and I became quite anxious. I was worried that I couldn’t catch up and handle the HKCEE. Luckily, after I recuperated, I was able to catch up by investing more efforts and I got to join the school’s mock exams. The results from the exams were passable. It showed that even though I missed school for a month, my hardwork helped keep the affect to a minimum.

As I prepared for the mock exams, my doctors discussed with the school’s physiotherapist about my rehabilitation at school because I still hadn’t recovered. After their discussion, I was asked to follow the doctors’ orders and go to the school’s physiotherapy department every day after lunch to

do rehabilitation exercises for 20-30 minutes, to enhance my health. The exercises included walking, stairclimbing and stretching.

During the stretching exercises, the physiotherapist would lift my calf and stretch it. But as my thigh’s tendons were very stiff, whenever the physiotherapist slightly stretched my leg, the piercing pain in my “tendons” would shoot down my calves and knees. I didn’t mean to cry, but it was so painful that tears just flowed from my eyes, without ending. I was so embarrassed! And yet for classmates that were immobilised due to their diseases, not only did they have to go through these stretching exercises, they also had to wear leg supports to keep their limited mobility from rapidly deteriorating and their legs from deforming.

There were also classmates who had to be tied down to the bed by the physiotherapist—in a way similar to how inmates were tied during transportation in old Chinese dramas—to help them practice standing. These standing sessions lasted half an hour to train the strength in their lower body and legs. Their faces certainly showed their discomfort, and yet they never moaned, unlike me who was so lame I got teary eyed. For them, they had but one goal—to maintain their mobility and physical condition, slow down deterioration, so that they could continue their fight academically and elsewhere. I was stunned and impressed by their super-human perseverance, and I was ashamed of myself. I decided to learn from them.

THE DAY THE RESULTS CAME OUT

I successfully joined the HKCEE afterwards and waited patiently for the results. When the day arrived, I found that my results were eligible for the matriculation course. I was relieved. Mr Lo, the social worker, said to me, “You said you were worried that you couldn’t adapt to the new subjects, and yet you did it!”

Unfortunately, the school was not offering any matriculation courses this year, and so we could not continue our studies in the same school and had

to look for schools elsewhere. Fortunately, in the company of my mother and Mr Lo, I found a mainstream school that would grant me an interview at the Joint Admission Centre. This was even a newly established “millennium school”. After the interview, I saw my mother chatting with Principal Chan from my previous school, the one where I studied before I underwent the scoliosis correction surgery.

When Principal Chan saw me come out of the interview room, he immediately asked if the school had accepted me, and told me that his school still had two places left in its arts classes and could take me in directly. But since I was already accepted by this “millennium school”, I thanked him for the kind offer. He said something to me that I remembered till this day. He said, “You don’t need to study in a famous school. As long as the learning atmosphere is good, you will be motivated and earn good grades.” It was such wise advice that guided my subsequent school selection. I would find a school that truly suited me and not go for “excellent schools” based on fame. I was going after knowledge and not the school’s eminence. Even if I was lucky enough to join the school, the fierce competition between classmates would only add to my stress and I may not attain the results I deserved. The principal’s words became my guide to school selection.

I visited the new school right after leaving the Joint Admission Centre. I found that the school was well equipped, the road was flat and the environment beautiful. From the third floor, I could even see the whole Rambler Channel and appreciate Tseun Wan from afar. Although I was not studying there yet, I was already excited about the new school. The campus was designed with accessibility in mind. Every floor had disabled toilets and lifts, which were just what I needed. This is where I would begin my new academic life.

MY YEARS AT JFKC

During my year and a half at JFKC, there were a few incidents that deeply impressed me. I can still remember them vividly. And I would like to share them with you.

After my scoliosis correction surgery, I convalesced at home for half a year before I regained my strength. Normal grammar schools no longer suited me. My original classmates had all progressed to Form 5. They were all hard at work preparing for the open exams in two months and I couldn't catch up to their progress after suspending from school for six months. Based on these considerations, I decided to change to a school that catered special needs. Part of the reason I chose this school was because it had experience caring for students with physical disabilities. I was better protected at this school and could rest and recuperate. I needn't be as "combative" as in my old school either. Another reason I chose this school was because it allowed me to repeat Form 4. I could relearn some of the subjects and have more time to prepare for the coming year's HKCEE. It was killing two birds with one stone.

Academically, after starting senior secondary school, somehow I had trouble solving maths equations. I didn't know whether it was because of my deteriorating health or because HKCEE maths was more difficult than that in junior secondary school. My grades in maths exams dropped significantly, and I was often wavering between passing and failing. I was despondent about it. The biggest challenge for me at this school was still maths. No matter how hard I tried, I was still behind my classmates. At several exams, I was a few marks from passing. I was dejected, and thought of giving up on this subject.

One time, the maths teacher, Ms To, offered to tutor me outside of class. I was absent-minded during the tutorial. Ms To caught my inattention and asked, "Do you want to give up on maths?" I admitted, "I feel powerless with maths, I really want to give up." I remember she said, "If you give up and shirk away at the slightest setback, that's not good." The words hit me hard; I

was ashamed and I blushed.

After the tutorial, I returned to the classroom and hid my head on the desk. Thinking back at the incident, I felt that if I really told Ms To I wanted to give up, I would let her down. She had taken time out of her busy schedule to tutor me, and yet I wasted her time, kind intentions and efforts. I would let myself down by such cowardice as well. I wept.

After the incident, I was determined to get passing grades in maths and not shirk from the challenge. I studied math theorems, equations, did exercises, especially repeatedly answering questions on past papers. I wanted to hone my skills so that I could do better at exams. When I encountered maths problems I did not understand or could not solve, I would seek the advice of Ms To or classmates in the upper forms. They would all gladly answer my questions, and impart some tips. Some of them would even meet me at the school canteen at night to pass on their knowledge, patiently explaining some maths theorems and how to apply them in solving equations, as well as my on-going frustrations. I made significant progress in maths, and my grades soared. The "extraordinary" grades I scored at the HKCEE were thanks to Ms To's encouragement and guidance, and my classmates' generous teachings. I still cherish my fellowship with them.

Apart from learning, there were many exciting dorm activities to enliven our daily life and lessen the pressure and anxiety from school work. The activities allowed us to relax and recalibrate ourselves, to live more healthily. One of the most memorable activities was a singing contest held at the end of the school year. It was because, for reasons unbeknownst to me, I was elected by my classmates during the preparation process to be the emcee of the event. I was not an articulate person, and I was worried that I would do poorly and ruin their show. I wanted to decline, but they were very insistent that I had no excuse but to take on the duty.

On event day, when I picked up the microphone to introduce the contestants and their songs, I was short on breath and my voice came through weakly even through the microphone. The contestants and audiences could not hear what I was saying and looked confused. One of the

school's physiotherapists saw this and said, "Who picked someone who is too weak to speak to be the emcee? Now you can't hear what he's saying." He was telling the truth; he deftly pointed out my weakness. But saying it so publicly was brutal, and I was hurt. But I was competitive, I didn't want to lose after what he said, so I held on. I bellowed out the contestants' names into the microphone, so hard that I didn't care if I hurt my throat or vocal cord; I needed to win. I wanted to prove to him I could do it if I wanted to and shut him up with my actions. Now that I think about it, I was too emotional; hurting my throat like that was unnecessary. After that incident, I no longer tried to act tough. Speaking was not my strong suit in the first place, so I was innately handicapped. I was also always scared of socialising with others, I was not a smooth-talker and I would easily offend others without knowing it. So whenever my classmates wanted someone to speak on stage, I would stay silent and let them sort it out.

I still remember this one time when my class went for a school trip to Sai Kung and the nearby Wong Shek Pier. Aside from enjoying the beautiful scenery, the teachers and students had a sincere conversation. We talked about our plans and aspirations. Two or three classmates said they wanted to study computer at university and become programmers, to develop computing technologies to enhance the disabled's quality of life. Some of the classmates' dreams have already come true and have become software developers, realising their future in software development. When they asked about my dreams, I naively said I wanted to study Food and Nutritional Sciences at the Chinese University, because I really loved eating, so I wanted to major in this subject. I wanted to study the composition of different foods and design menus high in nutritional values for people to enhance their nutrition intake and maintain better health.

Yet years have passed and I have taken a vastly different path. I picked the Chinese department, completely unrelated to my original dream. Why did I make this choice? For one, the admission requirements of the Chinese University's Food and Nutritional Sciences Department were quite demanding. My A-Level grades were some ways away from their median admission grade. More importantly, students needed a basic knowledge of

chemistry, but I was an arts student. I didn't study chemistry after junior secondary school. So my existing qualifications did not meet their entry requirements.

I never expected not being able to live out my dream, so I could only let it go. There is no turning back. Thinking about it now, it was a pity that I did not get to take part in nutritional research, to improve my health and that of others. But there was no other way. The Chinese I now study gives me exposure to ancient China's political and cultural systems and lets me traverse among the literary worlds of Tang poetry, Song Ci, Yuan opera and Ming and Qing novels. That is quite enjoyable. So I will tuck my childhood dream deep in my heart and savour it again some day.

That day, a few classmates also talked about their feelings about me. Two of the classmates had known me for a year and a half, but they still felt I was mysterious and couldn't understand what I was thinking. They felt a sense of separation, an abstruse alienation. I responded that I was someone who needed a long time to become warm up to others, so it wasn't surprising that they felt that way. Now that I think about it, apart from those reasons, there was an even more important reason.

After transferring to the JFKC, many of the subjects I studied before were no longer available, and I had to make a hasty switch to other subjects. I had only elementary knowledge of those new subjects and my thoughts were jumbled. I couldn't formulate a clear concept and system about the subjects and had to spend a lot of time understanding and learning, conceptualising and voraciously catching up. For that reason, I didn't spend as much time with the classmates and that caused the alienation. No wonder they had that feeling about me.

Another incident worth mentioning is that, after the HKCEE, we organised a distinctive appreciation dinner for the teachers. In normal grammar schools, most HKCEE and A-Level graduates would also organise appreciation dinners for the teachers. They would usually pick a hotel or a restaurant to organise a banquet or a buffet to thank the teachers for their guidance

and nurturing over the years. But we didn't do that. We followed JFKC's tradition and organised the dinner at school. All the students handled the preparations, from sourcing ingredients, decorating the venue, all through to designing and cooking the dishes. Everybody was responsible for a part. I was assigned to buy the ingredients, utensils and decoration supplies, and to act as the "sous chef" when other classmates cooked the dishes and help them prepare the ingredients.

The buying part went very well, but a funny incident happened when I worked as the "sous chef". I was helping the classmates make sandwiches. I placed a piece of bread on a big plate, scooped out the tuna pate from the can with a knife and forcefully spread the pate on the bread two to three times. After that, I placed two pieces of bread on top and robotically repeated the procedure. Before long, there were two nine- to ten-inch-tall "bread mountains" in front of me. Some of the classmates who were making desserts nearby joked, "You don't seem to be adding the spread, you seem like plastering walls and building an apartment!" As they were laughing, I paused to look at the two towers of bread on the tray. They were exactly like two white buildings, and I laughed too.

The whole process took two weeks to complete. On the day of the dinner, we prepared a sumptuous buffet for the teachers, therapists and janitors. We had a feast—fried rice, Swiss chicken wings, noodles, skewers and sandwiches, and duck's tongue and jelly fish prepared by some classmates' parents. For dessert, we had jelly, mango pudding and tofu pudding. Though it was not as tasty as the hotel's, seeing the teachers, janitors all enjoyed the meal and that all the food and drinks were gone made the hard work in the past couple of weeks worthwhile. During the preparation process, I also understood the importance of communication and teamwork. Many classmates worked very hard on the preparations, often till late at night. All they wanted was to host a smoothly-run, successful appreciation dinner for the teachers. And they did it.

In my year and a half at JFKC, I had the chance to meet many physically disabled classmates. I understood that although they were handicapped,

they held unabashed pride. Their behaviour taught me what it meant to be handicapped by body but not by soul. I was touched, and lifted by them. It gave me the courage to come out of my ravine and set sail again. If it wasn't by chance that I had to undergo a surgery and recuperate for a long time, that I had transferred to this special school, I wouldn't have met these resilient, persevering, courageous classmates. They lived life to the fullest and showed us how it was done. If I hadn't met them, I probably would never see the many colours of life. For that, I am very grateful to them for teaching me what it meant to live a full life when I was still young, and what it meant to live in the moment.



THE JOURNEY TO DISCOVER MALAYSIA

I travelled for the first time in the summer of 2002, when I was studying in the special school (JFKC). The school always entrusted travel agencies to organise tours to visit places that were suitable for the disabled. When I was still able to walk, I wanted to achieve my dream of travelling. Therefore, my father and I joined this “Special Tour”.

There were more than 30 people in the group, including a social worker from the school a houseparent, and a dozen students and their parents and siblings. All of us gathered at the airport to check-in. We boarded an Airbus plane and headed toward our destination, the capital city of Malaysia, Kuala Lumpur.

SPECIAL ARRANGEMENT FOR BOARDING

Due to our limited mobility, many of us needed wheelchairs. Some of us even had to use respirators to keep breathing. (For me, I only needed to use it at night but not in the morning.) To help us board, the airline allowed us to enter the cabin before the other passengers. They provided us light and foldable wheelchairs for us to sit comfortably in, and the ground crews took us into the cabin to look for our seats. They also transferred us from the wheelchairs to the seats. I felt terribly sorry for getting them soaked in sweat during this process!

MY FEELINGS OF THE FIRST FLIGHT

The airplane was soon ready for take-off after we settled down. The broadcast reminded us to fasten our seatbelts. The flight attendants provided us some earplugs too. Wearing them could prevent us from being nervous and feeling unwell when we hear the loud noises during take-off.

Since this was my first time to travel abroad and travel by plane, I was very nervous and excited. It took three hours to go to Kuala Lumpur, and I was afraid whether I could adapt to the cabin environment and the seat.

(Compared to wheelchairs, the seats on the plane were harder and less comfortable. For skin-and-bones disabled people like us, we would be aching all over after sitting for prolonged periods. Thus, flying was definitely a challenge to us.) Even so, it was so exciting that I was able to achieve my dream to travel abroad. I could leave my homeland, Hong Kong, and explore an unfamiliar foreign country, a place where I knew merely a little bit about. I only read about its people, customs, cuisine, geography and climate from books.

Having an opportunity to understand the local customs could significantly broaden my horizons. I was like an adventurer, who ventured into an unfamiliar territory to explore and fulfil my desire of exploration.

When the plane took off, my chest was uncomfortable, probably due to my small lung capacity. So, I held an air pump in hand, planning to use it whenever necessary, to provide me with sufficient “nutrients” to finish the three-hour flight. Luckily, the air pressure in the cabin was acceptable, and I did not need to use the pump to help my breathing in the end.

About 50 minutes after taking off, the cabin pressure was stabilised, and I could take a rest.

When the plane flew over the South Pacific, the flight attendants gave out lunch. Some friends told me that “airline meals” were quite tasty and the selection was wide. So I was curious and hopeful about “airline meals”. But before long, my dream was shattered. The food was not as tasty as I thought and there were only so many dishes to choose from. Not to mention the “airplane meals” only left me half-full, so it was mostly just to keep me from starving. I was somewhat disappointed.

DIFFICULTIES OF TOILETING ON PLANE

As the plane neared the Kuala Lumpur airport, my father led me to the toilet so we didn’t have to search for washrooms in the airport. Although the toilet on the plane was small, it was well-equipped. Other than basic fittings, like

a toilet bowl and a sink, there were a mirror and a cupboard for passengers to freshen up themselves. However, for the disabled, toileting on the plane was not pleasant. This space was so small that we could hardly move. I had nothing to hold on to due to the lack of handrails inside, so it was difficult for me to stabilise myself. I had to lean onto my father to maintain balance. Besides, the toilet was too low. As someone quite tall, I felt I was stuffed into the toilet. This was toilsome. I hoped the airline could set up a disabled toilet in the cabin to reduce the difficulty of toileting for us disabled.

ARRIVAL AT THE KUALA LUMPUR AIRPORT

After arriving, the cabin crew arranged for the others passengers to leave the cabin with their personal belongings as usual. After that, they arranged for us to sit in Business Class which was nearer to the exit. We then waited for the ground crew to retrieve our wheelchairs from the cargo hold before disembarking the plane. The travel agency had already sent two tour guides to welcome us once we exited the gate. A car was also arranged to collect us. With that, the amazing five-day journey officially began. In these five days, I was deeply impressed by Malacca. Since it had been ruled by the Dutch before, the buildings there had a strong continental architectural style.

The Strait of Malacca is so beautiful!

It was already evening when our car arrived the Strait of Malacca. After dropping off our luggage in the hotel, we immediately had our dinner in the restaurant inside the hotel. Then, my father and I went to the front door of the hostel to enjoy the unbeatable sea view. The hotel was located on the opposite side of the Strait of Malacca; we could enjoy a view of the entire sea. The endless sea was like a blue mirror. The sea and the sky seemed to merge. The view was so spectacular that shocked me. There were some ships slowly passing through the mirror, and the whole scene was serene. The Victoria Harbour in Hong Kong was no match to the Strait of Malacca. The differences were stark—the Victoria Harbour could merely define as a river instead of the harbour after reclamation.

On the next day, we visited some European style architectures, including

churches and houses. Since they were in vermilion, they were called “The Red House” or “The Red Buildings” by the locals. All these architectures were built when the Dutch governed Malaysia, and they were the oldest buildings built in the East. The Christian church was built between 1641 and 1660; and the neighbouring Catholic church was built in 1753, which was some 350 years ago. Why were all the walls of the red? It was because the red bricks were transported from Holland to build houses nearby. Thus, this cluster of buildings were named “The Red Buildings”.

ASSOCIATION OF THE MILITARY CAMPS

We passed through the area of the military camps and were ready to leave by coach. When we got near the military camps, we saw soldiers repairing their firearms. That was my first time to see such a large number of guns and bullets closely. I immediately thought of burning battlefields. The soldiers checked their weapons and inserted bullets for backup at the same time. There were machine guns near the soldiers. The 100 or so bullets were in golden colour, and they were arranged in a very long row. At a glance, each bullet was a few centimetres long and three to four centimetres wide. It was not difficult to imagine its destructive power.

This naturally reminded me of wars. Deaths and casualties are common in wars. These machine guns were murder weapons. I felt a sense of hatred developed in me once I saw the guns. I wondered about the person who invented this kind of merciless arms that are more horrible than ancient firearms and arrows and bows. I just hoped that the world would be peaceful and different races could set aside their histories and prejudices and coexist harmoniously. Then there would be no need to harm the innocent with these weapons. Unfortunately, large and small disputes between countries have never ceased. It seems that this is the way since ancient times. For some regions, wars happen frequently. (For example, when I was travelling to Malaysia, the United States was attacking Iraq. The war was in full swing and both sides suffered enormous casualties. Iraqis were displaced and became refugees. The production of the whole country stopped and dwindled into chaos and panic.) I could not help but imagine the awfulness and cruelty

of wars. I thought about the ugliness, selfishness and greed of humanity. I felt a sense of insecurity and horror, and I dared not to look at the guns again. I decided to leave immediately to prevent having any further scary imaginations.

FEEL LIKE I WAS IN A MEDIEVAL PALACE

Another place worth mentioning is the Malaysian Palace. It is a squared structure with a spire on its roof, where a national flag flies. In the centre of the building is a big green garden. The colours of the buildings and the White House are similar; both are in milk white. The palace complex and the exteriors are in a creamy white colour like the US White House, projecting a solemn and sacred feeling. I was most interested in the soldiers standing atop the city wall. They all dressed in tidy white uniforms and carried western swords. They seemed like the warriors in the medieval age. They were patrolling around the city wall, safeguarding the king.

At the entrance to the palace, I saw majestic cavalries guarding every doorway. They looked like gallant medieval European cavalries. They controlled the horses by bridle reins to prevent them from running amok. They also carried silver swords and wore white starched uniforms, looking handsome and dignified. They also had a special mission: to be the king's Goodwill Ambassadors by taking photos with visitors from around the world. They had a huge responsibility.

ORIGIN OF THE MALAYSIAN KING

The tour guide told us that Malaysia originally had 13 kings, who were the 13 high lords. They later followed the will of the people and relinquished their power. The people then elected a president to manage the military and the country's financial affairs. In return for the kinds' willingness to forgo power, a palace was built to let them to live as kings and royalty. A portion of the taxes was also allocated to enable the kings to enjoy a regal life.

The king would be changed every four to five years, so that the 13 high

lords could enjoy their shares of living in the palace and having regulations designed according to their needs. These were done to appreciate the kings' return of power to the people.

The tour guide indicated that we could know whether the king was in the palace if we took a careful look at the location of the national flag. It was custom that the flag would be at the top of the flagpole when the king was here; or lowered to half-mast if he was not. On the day I visited the palace, the flag was raised to the top, indicating that the king was in the palace.

THE LOCAL DELICACY: BREADED CHICKEN

Most of the participants of this trip were disabled like me. We had to travel around in wheelchairs. As a result, we did not visit as many landmarks as the ordinary tours. To compensate for the loss in sightseeing, we ate more. In fact, this was an "eating trip".

As the saying goes, hunger breeds discontent. For those of us from South China, we are discerning about our food, demanding colour, aroma and taste. Since arriving in Malaysia, other than having buffet for breakfast, we ate in restaurants or cooked food stalls, or bought some unique local foods to cook ourselves to experience the Malaysian eating culture. Breaded Chicken was the most distinctive dish. Its cooking method is alike that of the Chinese Beggar Chicken. For the Chinese Beggar Chicken, it is tightly wrapped in pond scum and lotus leaves, sealing the chicken inside. After braising it, the pond scum and lotus leaves are removed, and the chicken with the aroma of lotus leaves is ready to be served. For the Malaysian Breaded Chicken, some secret sauce is first smeared onto the chicken and it is wrapped in plastic wrap. After that, the chicken is placed on flour and rolled into a super-size flour ball. It is then baked for about an hour and served.

Our group of 30 people were divided into three to four groups, and waited for the delicious food. When the Breaded Chicken was placed on the table, all of us felt curious since we did not know what was inside the giant bread. We could not wait and used our knives to dissect the bread. Seeing a chicken

wrapped with plastic wrap, we immediately removed the wrap, tore the bread apart by hand and ate the sauce and chicken. The bread was even soaked with chicken grease. Our appetite was fully satisfied. It was probably because I was not accustomed to spicy food that I choked while eating. It only stopped after drinking water continuously. It was better if I did not eat so much.

MUTUAL LOVE AND HELP BETWEEN MEMBERS

The most touching element of the whole journey was the mutual help. Members helped each other to overcome all sorts of difficulties. Since half of the participants were disabled, their limbs were weak. Some had to walk with crutches. For that reason, the assistive tools among us were numerous and heavy. There were dozens of wheelchairs of different sizes. (To prevent affecting flight safety, wheelchairs could not be used on the plane). There were also around 10 respirators and air pumps, and an uncountable number of loose medical supplies. This was really a special tour. Throughout the journey, the parents would first take out the wheelchairs one by one from the coach after arriving at each tourist spot. They would pick up their children afterward and place them safely into the wheelchairs. Then, they would immediately go back to the coach and help the others or collect the luggage.

The tour escort, tour guide and driver also manifested their compassion. They volunteered to push the wheelchairs or pack the baggage. They would also walk to the door of the coach and remind the members to be careful, especially those who were carrying disabled children. I can still vividly remember seeing them selflessly helping and cooperating with one another to take good care of us. They sweated profusely every time, particularly the tour escort and the driver, when they moved the wheelchairs and packed the luggage. Their shirts, even their coats, were drenched. They all looked like men made with water. Yet even so, they did not mind. Instead, they smiled to us, like they were having fun. They were so kind. Their actions shortened the distance between us and for five days we became like family members—helping, accommodating and being considerate to one another. Thanks to everyone's love, help and partnership, the joyful journey ended impeccably.

As we arrived the airport, every family gave the tour escort, tour guide and driver gratuity to thank them for their selfless dedication, their help and a wonderful five days. Although it was only a small sum, it was a token of our appreciation. I believe that if there were mutual care, love, magnanimity and consideration among people, everyone would grow closer and become more understanding; and a harmonious and more amicable society could be built. This is what our society lacks today. I hope that this wish could come true soon.





CHAPTER 3

CHASING, FOLLOWING A DREAM TO STUDY IN UNIVERSITY— FROM MATRICULATION STUDIES TO UNIVERSITY

MEETING THE ANGEL OF MY LIFE – PRINCIPAL DOROTHY WONG MAN-WAH

Throughout my school years, I had met many “angels”. They helped me a lot academically, daily and financially. Ms Dorothy Wong was one of them. She was the former principal of the CCC Yenching College, the school where I had my matriculation studies. Other than helping me academically, Principal Wong also found people to help me purchase the life-supporting equipment which saved my life. It could be said she was the angel of my life.

I felt both happy and worried when I first started at the college. I was happy because I could start my matriculation studies and have a new beginning. I was worried since I had to adapt to this new environment. Building friendships with new faces was a huge challenge for me as I warm slowly to people. This inadvertently gave me some pressure.

THE ELEGANT PRINCIPAL WHO REVITALISED MY LIFE

The first time I saw Principal Wong was at the school year’s opening ceremony. Her speech was so eloquent. And her demeanour was like a classic British lady.

The first time I met her face to face was one morning a month later. It was recess time. Some classmates left the classroom to play while some stayed in the classroom to chat and hang out with other classmates. I was taking a rest at that time, so I would not feel tired in the coming lesson. At that moment, someone walked in through the back door. She came up to me and called me softly. I was shocked and woke up. When I turned around, my mind blanked because I saw my principal.

She wanted to talk to me about applying to the Sir Edward Youde Memorial Scholarships for support for purchasing life-supporting equipment. She had already obtained the quotations from two different companies for respirators and wheelchairs and had filled in the details in the application form. I had no

idea she was doing that. She courteously asked for my opinion after she had already prepared everything.

In fact, I should be the one filling in the form and requesting quotations as I was the one applying. But my principal did all that for me despite her busy workload. She was so passionate that I could deeply feel her sincere and tireless efforts in caring for the students. This was so heartening. From this incident, I could tell she was very different from those high up, commanding principals I had in primary and junior secondary school, who always kept a distance from the students and who we felt scared even by sight. For Principal Wong, she was very nice and caring to her students. She changed my perception towards “principals”.

By the second semester, I had to go to the hospital to test the new breathing machine. I stayed in the hospital for more than a month. This was totally out of my expectation. I was afraid that I could not catch up with my studies and it made me anxious. But there was no use to fret, as I did not even know when I could leave the hospital. All I could do was read textbooks and reference books in my spare time, so that I could catch up more quickly when I returned to the college. On the other hand, I was more concerned about the acquisition of my breathing machine. Simply, it was a financial problem. At the time, the Sir Edward Youde Memorial Scholarship still had not announced the results but using the respirator was an immediate issue for me. With double pressure, I was like a cat on a hot brick.

A few days passed and the hospital finally received the notification from the scholarship secretariat. After the panel’s discussion, I was only sponsored two-third of the cost of the respirator. The other one-third I had to bear myself. The wheelchair application was even being rejected. According to their explanation, the medical expense was too huge so it was not fully granted. The result gave me a headache. As the wheelchair was not a life-supporting device, it could be bought later. However, the respirator was. Without it, I could hardly survive. Unfortunately, the authority would only sponsor two-third of the cost. The remaining amount, which was about HK\$30,000, still had to be paid by me. Even if the medical equipment company allowed me to pay in instalments, my family still could not afford

the expenses. My family and I were at a lost, we did not know where to find help. Unexpectedly, we received a call from Principal Wong. She learnt about the incident and one of her friends was willing to sponsor the remaining cost of the respirator. We no longer had to worry about the money. I could also focus on my studies.

We appreciated what Principal Wong’s friend did. Because of her generous help, I no longer needed to worry about my life-supporting machine’s expenses. My mother and I wanted to express our gratitude to this person. We wrote a thank you card and wanted to give it to her in person. Yet Principal Wong told us that she was so busy that she could not come to the school. Until my graduation, we still did not hear any news about her. I want to thank Principal Wong for being the middleperson too. Without her, this problem would not have been solved so perfectly.

ALL-OUT SUPPORT ON MY STUDY

In addition to the respirator, Principal Wong also helped me a lot on other matters. For example, she ordered two desks which could be height-adjusted from an iron furniture company for me. One was placed in the classroom and one was placed in the geography room for me to use in class. She also applied to the HKEAA for me to have an extension of exam time during my College Entrance Examination (CE Exam).

During my time with Principal Wong, one incident left a deep impression. It was the day which my first CE Exam results were released. After receiving the results slip, I was completely shocked. It was a huge blow to me. I stared at the results slip and froze. I never imagined I would receive these grades: an F grade for English and a U grade for Political and Public Affairs. Failing English was reasonable since my listening and oral were poor, but getting a U in Political and Public Affairs was totally out of my expectation. My performance in this subject was very stable. Even if I did not perform as well as usual, I should not have been “bestowed” an unclassified grade. I was very upset at that time.

Right at this time, Principal Wong came to me and told me that a dozen

of newspapers would like to interview me, and asked if I wanted to be interviewed. Due to my bad mood, I rejected instantly. She respected my decision and requested the journalists to leave the school. Thinking back now, refusing to accept the interview was pushing Principal Wong into a dilemma. She had to offend the journalists since I was not in a good mood, and it may negatively impact the school's future development, particularly in promotion. I feel terribly sorry for putting Principal Wong under such stress that day!

After the release of the results, I felt confused about my future. With a failing grade in English, no university would enrol me. My doorway to university was shut right in front of me. All I could do was sigh. I did not want to pursue an Associated Degree or Higher Diploma as the tuition fee was too high and the opportunity to enter university low. It was meaningless to study these courses so I would not consider them for the time being. I just wanted to repeat Form 7 in the same school and retake the exams for English and Political and Public Affairs. I could retake the CE Exam in a year's time and attempt to get a place in university again. However, the competition was intense since places for repeating Form 7 were limited. I was worried that I could not get a place. Finally, a good piece of news came. The school informed me that I could remain in the school as a Form 7 student, giving me a chance to enter university. I was elated. I believed it was the arrangement of Principal Wong as the power of deciding who could stay was in the hands of the principal. I am grateful to the principal's support.

I passed both English and Political and Public Affairs in my second CE Exam, and could finally progress to university. With the results released, Principal Wong spent much time and effort writing a reference letter to the Chinese Department of Lingnan University, hoping that it would enrol me. And my wish came true. Before the JUPAS results were released, I received a letter from a professor of the Chinese Department, saying that I was given a conditional offer. I could finally start my university life in Lingnan University. This success was thanks to Principal Wong's reference letter, which facilitated my entrance to my preferred faculty. The principal's generous assistance had helped me overcome many obstacles. I will remember her kindness forever.

TAUGHT BY WORDS, DEMONSTRATED BY ACTIONS

Principal Wong also taught me a lot about getting along with people. While she was teaching us Western table manners in an annual gathering, she taught the boys to be gentlemanly and to take care of the ladies. For us, a group of teenage boys, we hardly had the chance to receive formal manner training. What we knew we learnt from our fathers. We barely knew about Chinese traditional manners, not to mention the manners of the Western gentleman. We did not even know what a "gentleman" would do. So Principal Wong used her own experience as examples to teach us. She said every time she went out with her husband, he would naturally open the door and hold it for her to pass first. She advised us to care not only about ourselves but also about the ladies; and be a gentleman.

I believe these words were meant to remind us not to be self-centred. That we should never just concentrate on ourselves and neglect those around us. That we should learn to be empathetic, to care about ourselves and the others, to understand the feelings of others and not just our own.

In addition to tutoring us by words, Principal Wong also spread her love through actions. The dreadful South Asian tsunami that took place during Christmas in 2004 shocked the world and robbed many people of their loved ones and their homes. The survivors were devastated. As we returned to school after the Christmas and New Year holidays, happily planning for the coming year and preparing for a busy year to come, Principal Wong brought up the tragedy at the morning assembly. After urging us to work hard academically, as usual, she mentioned the tsunami. She said although we were still young and had no financial means, we could still donate part of our pocket money to the homeless victims, so that they could feel our love while dealing with the adversity. She set an example by donating money first. We were moved by her words and actions, and we followed her example and immediately donated. Although there was only little we could do and our donation was small, we wanted to help with what we could. By spreading the love via donation, we hoped to send some warmth to the victims, so that they would not feel lonely when facing the natural disaster.

THE DAY OF RETIREMENT

Principal Wong officially retired in September 2008. She left the school where she had worked for three decades. In June that year, the alumni organised a retirement party for her. I was one of the participants. I saw many alumni attended this event. Some of them were already adults with families. Once they knew that Principal Wong was going to retire, they signed up to join this party to express their reverence to her.

That evening, the organisers prepared hundreds of red roses and gave them to the alumni. The most touching scene was when we queued to give the flowers to Principal Wong to show our respect and love. I also went up and gave her a rose to show my gratitude. Nothing needed to be said. I can still remember her words and actions and her help as if it all happened yesterday. I will not forget what she did for me.

I learnt about selfless love from Principal Wong. She cared not only about her students, but also the victims of the disaster. Her big-heartedness is worth our imitation. I hope to pass on the love Principal Wong had given me to the others, so that more people could feel the warmth. If everyone could give a helping hand to the needy, our society would have more love and less sadness. And we could achieve a more harmonious community.



FRIENDSHIP WITH CLASSMATES

When I was studying Form 6 and 7 in the CCC Yenching College, there were many classmates that helped me solve the problems I encountered. One classmate in particular had helped me deal with countless difficulties and problems so I could focus on my studies. Every time I travel down memory lane, I naturally think about him and our friendship.

The true, pragmatic and open-minded Uncle Tsuen Tak Tsuen (Sam Lau) was the classmate who helped me the most. People called him Uncle Tsuen. The reasons we called him “uncle” were because he was older and he was a long-time student of the school and one with the best HKCEE results. His was influential in class. For that reason, it was natural for us to call him Uncle Tsuen.

I met him at the Form 6 orientation camp. After the principal and teachers explained the details of the matriculation course and how it was necessary for senior students to share some of the school’s work and responsibilities, he came up to me to chat and introduce the facilities, environment and school life. He demonstrated his brotherly care for the new students. During our conversation, he even asked me to come to him if I ever needed help, and said he would try to help me as best he could. I felt he was kind, willing to help and I did not feel he was arrogant at all. It was rare to see such a classmate.

As school started, Uncle Tsuen always looked after me. At the time, I was still using my ordinary wheelchair and a lightweight respirator. If I needed to go to toilet during recess or lunchtime, he would push me to the washroom and back to the classroom. When we had geography lessons, he and another one or two classmates would take me from our second-floor classroom to the elevator, and go the geography room on the fourth floor.

I remember one time we had to go to the geography room but the elevator malfunctioned, and I could not go to the fourth floor. At first I thought of just going back to the classroom and self-study. But a classmate thought I

should not miss the class and suggested gathering a few classmates to carry me up to the fourth-floor geography room. Uncle Tsuen immediately agreed and summoned a few boys to help. I was afraid of troubling them and risking an accident so I turned down their kind offer.

But they insisted. I could no longer reject their zealousness and accepted their offer. Six boys including Uncle Tsuen took part in the plan. Two lifted the back wheels of the wheelchair, two gripped the armrests, one cleared the way and one stayed at the back to ensure everybody’s safety, preparing to help whenever needed. Uncle Tsuen was the one clearing the way since he was comparatively shorter and less strong. The six of them worked together and lifted me to the fourth floor. After moving up every half floor, they would put me down, take a rest, before continuing. We finished this difficult task after around 10 minutes. I really appreciated their help, but I felt sorry for exhausting them. They were wet with sweat. All of them were drenched.

Uncle Tsuen would also help me to buy lunch sometimes. For a few times, he even pushed me out of the school to let me have lunch with the classmates. He would also be my “private nurse” by helping me to control the respirator. This is because after I became weaker, I switched to using a larger respirator that was more complicated to control. The new machine had a safety feature, which would beep if it stopped operating for more than 30 seconds, to remind the patient or the people around to check whether there were any problems or anomalies. But such a design affected the order of the class and it had to be dealt with every time it beeped. Since the respirator was placed behind my wheelchair, I was not able to control it myself and had to rely on others to help to control it. Uncle Tsuen therefore helped me to turn it on and off, kill the noise, adjust the settings and charge the battery. He was like my private nurse, to keep an eye on my respirator during class.

Sometimes, he also served as my “sitter” by taking me home. Every now and then when my parents were not free to pick me up from school, we would ask Uncle Tsuen to accept this responsibility and he would always readily take up this “chore”. He usually found one more classmate to accompany him to help. After arriving my home, they would first let me stand up and walk to the office chair and sit down. Then, they would set the wheelchair aside. It

was only after everything was settled that they would relax and leave. They would even help to lock the door. If it wasn't for Uncle Tsuen's assistance those two years, I would not have been able to relax my mind and focus on my studies and pursue my university dream. It was because of Uncle Tsuen's help that I succeeded, and he made me the person I am today. Thank you!

Uncle Tsuen and a few classmates would sometimes chat and play chess with me during lunch. One time, as we were chatting, a classmate noticed that Uncle Tsuen's results slipped after starting Form 6, that they were no longer extraordinary. Out of curiosity, the classmate asked him why. Uncle Tsuen answered humorously, he said, "I've been stripped of my powers!" All of us broke out in laughter. It was indeed strange that his results had been mediocre after starting Form 6. He never got to a higher ranking. I always wondered whether it was because he was in over his head or he stopped caring about high scores so he did not work as hard.

Time flew and two years passed. It was the day when the CE Exam results were released. Uncle Tsuen did not get satisfactory results and had no chance of getting into university. Perhaps he knew this already, so he just smiled and said nothing. From this, I could see he knew how to let go, which was completely different from me. I cared deeply about the grades. In this incident, he showed his excellent character. He did not mind the fame or the title. He faced all these with calm. For me, I worried and fretted about everything all the time. His attitude outshone mine.

As the day came for my CE Exam results, when I went to school, I was surprised to see Uncle Tsuen and another classmate in the classroom. I was in awe. I was so touched to know that they had come back for me. I received the results slip and saw that the marks were enough to get a university offer and enter my favourite faculty. I breathed a sigh of relief. Everyone was very happy and wished me well. Uncle Tsuen also congratulated me for my dream come true, as I was going to university to continue to my study. I carefully put away my results slip and we left the classroom to another place in school to catch up. We also went to the teachers' office to visit our teachers and chat with them before leaving.

One afternoon two years ago, Uncle Tsuen called me and asked about me. I learnt that he was doing a bachelor's degree and he was only a semester away from graduation. I was happy for him. I hope to see him again at some alumni gatherings in the future.

UNIVERSITY IS ABOUT LIBERALISM AND INCLUSION

When I started university, I thought I could enjoy free and relaxing learning; that the workload and pressure would be less than senior secondary school. It was what the older classmates told us when they came back to the secondary school to share their university experience. They said, “Once you finish the A-Level Examination, you will find that the university’s learning atmosphere and environment are much better than now. There will be fewer assignments. The stress of exams will also be less since exams are not the major criteria for good grades. So, you have to work hard to enter university.” Their words left a deep impression upon me. I was looking forward to the learning mode in university and the free learning atmosphere. More importantly, I believed I could relax after becoming a university student. Yet, what I thought was wrong. The learning mode was free as we could choose the subjects and lesson time freely, but it was definitely not as relaxing as they claimed!

Specifically, the assignments were a far cry from what I imagined. Originally, I thought the amount of assignments would be less compared with secondary school. This was a big mistake! With no doubt, the quantity was less and each course merely required us to finish one to two projects. Even if you studied five to six courses in a semester, you only needed to do 10 projects at most. Wasn’t that great? In secondary school, I had to do more than 12 assignments each term. I was happy about it in the beginning. The small workload meant I did not need to spend much effort and time, so I was very joyful. But this was just my wishful thinking. My good dream was soon shattered.

In terms of quality, the professor would give us a topic and ask us to form into groups of two to three. Then, the professor would provide some guidelines or instructions and each group had to search for the suitable information to finish the report. We had to make a presentation in class and invite other classmates to comment. Comparing with secondary school’s

homework, the time and effort needed were so much more. The most shocking was that each report required writing around 3,000 to 5,000 words, and this was only the minimum requirement. I was horrified that I had to write over 10,000 words in one semester. It was out of my expectation. I was afraid that I could not finish the assignments in time, and I would not be able to graduate. Due to my illness, I had to sleep for 12 hours a day to have enough energy to deal with my daily activities. The total lecture hours in university was 4 or 5 hours a day. After deducting the time consumed by other activities, I doubted how much time would be left for me to finish the assignments.

At the same time, I was not familiar with typing Chinese on the computer and had a slow typing speed. I could merely type three to five words a minute and I often typed wrongly. How could I type 40,000 to 50,000 words a semester? This was pressure for me, and I felt powerless. With this anxiousness and stress, I began my three years of hard university life.

In addition, I faced a difficulty when I needed to find groupmates. Since I had physical problems, I had to overcome more obstacles finishing and presenting reports than the average students. I was also shy and rarely initiated a conversation with other classmates. I did not know what to say to unfamiliar classmates and was often at a loss for words. I felt embarrassed, and it put me at a disadvantage. At my first tutorial lesson, the professor asked us to form into our own groups. Most of the classmates did that very quickly, only I and a few others had no groups. I was extremely worried seeing this situation. I did not know whether they would like to be my groupmate but I did not have the courage to ask. I was like a cat on a hot brick; I wanted to escape but could not. At this moment, a classmate, who was plumper in physique, came to me and asked, “Do you have a group? If not, can I form a group with you? My grades are not outstanding and I hope you will not mind.” I was astonished and I thought he was my saviour. I was just glad to have a classmate who was willing to be my groupmate. I said yes immediately.

I found that this classmate’s pen name was Fruit. He was a Year 2 student who promoted to university from an associate degree. We became closer

after spending more time together. Academically, he was my ally. We often formed a group in tutorial class. He helped me a lot with my studies. With his assistance, I finished one tutorial report after another.

I was not as lucky in another tutorial class. No one wanted to form a group with me. I did not know what to do and planned for the worst: to finish the report on my own. Though I doubted my ability to complete it by myself, since I had neither the ability nor the experience to take up such responsibility. After class, I went to a garden with my mother. I was depressed and had no way of releasing my pent-up emotions. My mom comforted me and said she would help if no one would. Yet even so, I did not think this was practical. The problem of not having groupmates had to be solved. I could not complete every report by myself, this was impossible. So I decided to tell my lecturer about my situation, and figure out a solution. Luckily, the professor was very nice. After understanding my concern, he suggested a feasible solution, that I could choose my own topic for the report and I did not need to do the presentation after finishing the written report. The problem was solved, and I was relieved.

I slowly adapted to the learning mode of university. For the reports, I gradually handled them with ease. I also met two new classmates who accompanied me to complete the assignments. One was Wai Tung, who was tall, handsome, but as reserved as I. Another one had a nickname called The Mad Monk (Tim Choy), who was always clear-eyed, direct and no nonsense. He taught me a lot when we were doing the reports, so I did not waste time and made fewer mistakes. Thanks to their help, I could overcome the challenges. My Chinese typing speed also improved, from three or five words per minute to around 10 a minute. I made fewer typing errors as well. It was a great step for me since I typed with a single hand. After facing failures again and again this year, I was more confident in handling my school work. I could even finish some reports by myself and without other's assistance. My academic results improved significantly.

Indeed, studying in university required spending enormous time to gain a little, especially in subjects related to language. Huge amount of readings

and literary works had to be read to improve one's mind and enrich one's knowledge. It was like the scholars in Han Dynasty who had to read for many years to understand what a book was talking about.

Although my time in university was tough—often needing to read a large amount of course-related materials and the teaching schedule was very hectic (as the school year spanned around half a year, so everything must be finished in a short time); and that sometimes I needed to work overnight to complete my papers before deadlines—it was a worthy experience. I came to university for knowledge, to learn more new things and listen to new points of view from the lecturers, to inspire my mind and enrich myself. Just as what Confucius said, “Knowledge, like a sea, is boundless.” Learning is a process in which you would fall backward if you did not move forward. Studying was a student's the basic responsibility, not having fun or wasting three years. If that was the case, there was no point studying in university at all.

That said, we needed to have entertainment to balance our daily lives and maintain a better mood. For that reason, I joined some extra-curricular activities after school, such as university forums, talks about tea ceremony held by the Chinese Department, and farewell parties. This matched the university's concept of whole-person development.

The university forum would invite celebrities in town or someone who had special experiences to come to school to give a speech. They would interact and have honest conversations with students. The objective was to broaden the students' horizons by letting them meet different people and learn about different issues, for them to learn from the speakers' experiences and prepare themselves. Of all the speakers who came, I was most impressed by Ms Maria Tsang and the young survivors of the Sichuan earthquake. I was inspired by their experiences. From these talks, I learnt that we should not be discouraged by setbacks. Instead, we should pick ourselves up, dust off and start over. We should follow their indomitable spirit and never give up.

I also participated in a talk about tea ceremony organised by the Chinese

Department. An expert was invited to introduce the techniques of brewing and making tea. The speaker even invited some audience members to try to make a cup of tea and imparted some tips. He also brought different types of tea leaves, such as Pu'erh tea and Jasmine tea, and made tea for the participants to try. I was most interested in the Lan Elegant Tea, which is a type of green tea. According to legend, after Empress Dowager Cixi tasted the tea, she named it Lan Elegant after herself. The tea is distinctive for its sweet and aromatic taste, and it can soothe the throat. When I tasted this tea, I smelled a fresh fragrance and it filled my mouth. It was so refreshing and tasty that I finished it in a gulp. It was very relaxing. Since it was so delicious, I could not stop until I drank several cups. Other than having an opportunity to taste good tea in this activity, I got acquainted with those who were also from the Chinese Department. It was fun and enjoyable.

When I was a Year 3 student, I attended the farewell party of the Chinese Department organised for the students who were about to graduate. On that night, we played games, shared our thoughts and chatted about things that happened in school. There was a lucky draw session, and I received Professor Sitou's book, which contained her well wishes and signature. I was very happy. The gathering ended late into the night. I will never forget this farewell party.

I also had a great hostel life. Sometimes, I would invite my friends to my little room to have hotpot, hang out and talk about our studies. Fruit Kong, Wai Tung and the Mad Monk (Tim Choy) were regulars. Aside from school, we would also talk about movies. I would sit aside and listen to their views. Sometimes they would even become animated, and it was very enjoyable hearing them talk. They would also chat about things I had never heard of before, like learning guitar, the results of the English Premier League football, and overseas cultures. These not only widened my horizons but also showed how talented and knowledgeable they were. So, living in a hostel not only gave me more time to study in school, as it spared me from long distance transportation, it also allowed me to make more new friends. Hostel was a good place for gathering. Classmates and friends could come and eat and chat with me, and we could become closer.

As a whole, I tasted sweetness and bitterness in these three years. Academically, I was frustrated when I encountered unfamiliar subjects, like Chinese phonology. I knew nothing about the Cantonese pinyin and *fanqie*. No matter how hard I learnt, I still could not master it. I could not figure out which tone the Chinese word belonged to. It was depressing and sad. Yet these obstacles were inevitable in learning. Everyone has their strengths and weaknesses, and we cannot always master what we learn at once. Repeated trainings and exercises are needed if we are to master the skills.

I knew I was not talented in language. I could not study Cantonese pinyin, Putonghua pinyin and English pinyin well. I have already surrendered and hoped these subjects could forgive the stupid me. Although I needed to spend a lot of time reading, often until late into the night before I could finish and rest, I was contented when the views or standpoints of the author inspired me and when I could make use of their opinions in my assignments. No matter the cost, it was worth it. The departmental and hostel activities acted as "lubricants" which helped me to relax within my hectic schedule. I could expand my social network by making more new friends and broaden my horizons through acquiring knowledge outside of the books. These were extraordinary and I found my university life enjoyable.

Three years of university life had sweetness and bitterness, as in life, there were ups and downs, but this is life.

HIS LIFE, MY INSPIRATION

Attending lectures at university aside, I took up some extra-curricular activities, such as the Integrated Learning Programme (ILP) organised by the Student Service Centre (SSC). I attended different talks to enrich my knowledge and expose myself to the world.

Some of the forums invited well-known people or those who had special experiences to come and share. We heard about how they overcame adversity and handled challenges, turning crisis into opportunity. We expanded our knowledge, strengthened our fortitude and learnt about crisis management. The talks were very rewarding.

The most impressive one was when several young survivors of the Sichuan earthquake shared their experiences. I was greatly inspired, and it enhanced my confidence in facing and coping with challenges.

PERSEVERING AND COURAGEOUS SICHUANESSE TEENS

For the young people who survived the earthquake in Wenchuan, Sichuan—who were so close to death—many of them were injured, and some even needed to undergo amputations. Although they suffered such pain and lost their homes at such a young age, they were not dispirited. Instead, they worked hard to learn to use their prostheses. Despite falling during practices, they stood up and continued practicing, to master using the new limbs and resume walking as before. This spirit was admirable. I also had a similar experience. At the onset of my disease, my legs were weak and could not support my “heavy-as-a-ton” body, and I could hardly walk. Not only that, my spine later curved into an S-shape and I would easily lose balance and fall. One time when I was in the corridor outside my classroom, a classmate from the neighbouring class ran into me, and I fell backwards. My whole body ached and the pain lasted for a few days. Since then, I walked slower to reduce the chance of falling. For most of the time, I just stood up or sat down. I would not walk unless it was necessary. I became lazy. But these teenagers had a completely different attitude. They conquered the obstacles

with perseverance and courage, standing up after falling and never gave up. It was an honourable and admirable spirit.

After they could walk smoothly, they contributed to the reconstruction of their hometowns. One and a half years after the incident, they accepted the invitation of a Hong Kong organisation to come to Hong Kong to share their experiences and spread the message of life is precious. Their coming let the Hong Kong people feel their passion towards life, reflect their own weaknesses and rethink the meaning of life. Their trip was also an opportunity to raise funds for Sichuan to help them to rebuild their homes and improve their quality of living.

They talked about their dream occupations as well. For the younger ones, they wanted to get into university and go back to Sichuan after graduation. They wanted to use what they learnt to teach the next generation and contribute to the homeland that raised them. I saw the determination in their eyes, a proof that they would work hard for their goals. For those who had entered Beijing University or Nanjing University, it was lucky for them not to be present when disaster struck. But they were deeply sorrowful seeing their families and friends suffer. They decided to contribute their knowledge to their hometowns once they graduate and build a better homeland. I was pleased to see that they have such a big vision and I believed they would succeed. At the same time, I hoped I could fight for my dream as hard as them.

The teenagers said the tall and beautiful buildings in Hong Kong reminded them of the horrible scenes of the earthquake. They were having lessons at school when the earthquake occurred. Their minds blanked and they barely followed their instincts to escape. Many students who did not leave fast enough died. The survivors were the luckier ones, but many of them had limbs pinned down by rubble and had to undergo amputation after being rescued. They were still terrified by the ordeal, and images of the earthquake still lingered in their minds. Hopefully, time will cure and comfort them.

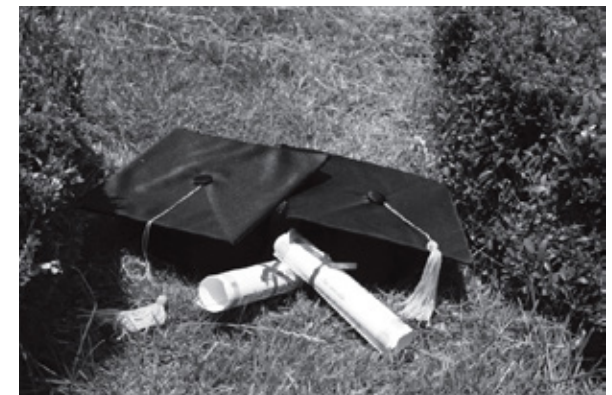
I also had a similar scary experience, but it was not until recently that I start to comprehend its meaning. Over the past few years, many classmates I met

at JFKC passed away after their health deteriorated. Aside from feeling pity for them that they could not live out their aspirations, I suddenly realised that death is so close to me. The horror of death terrifies me. Twice I nearly died when I was a child but I finally won the battle with my will. Perhaps because of my naivety, I did not feel the horror of dying. But now that I have grown up and have seen more, I started becoming scared of death.

Watching and hearing my old schoolmates pass away after ailments or minor accidents made me realise that human life, no matter how superior, is fragile. We could die because of an ailment or a minor mishap. What is the true meaning of life? Should I have fun while I can or insist on my goals? I kept thinking about this question but still could not figure out the answer. That is, until now. If life has so many uncertainties and death is an inevitable part of life, then I should not panic or worry about it, nor should I try to conquer my fear of death. I think everyone is scared of dying, just that the intensity differs. So just let death exist. It is a part of life. I should enjoy the moment and strive to pursue my dreams and aspirations, and not squander my time in this world. I would also not waste what the world had given me in raising me and the love of my relatives and friends.

When the sharing session ended, they left the stage with a hobble. Each step they took showed their efforts and it was a proof of their will to live and fight for their future. It was a touching moment. At the end of the talk, my mother and I decided to buy a book written by them about their experience in the earthquake to show our support for their will to live and dedication to their goals.

From the sharing, I could see the teenagers' perseverance and fortitude in overcoming difficulties and challenges to achieve their goals and dreams. I thought they were courageous warriors. Their acts inspired me and boosted my confidence. Even though I would be facing bigger obstacles in the future, I would be as brave as them and I would smash all the barriers in my way to realising my dreams.



BEING ABLE TO BREATHE IS A DIVINE GIFT

The respirator at the back of my wheelchair had accompanied me for more than six years. During this time, it had helped me breathe and injected endless vitality into my life. It was a competent assistant. However, sometimes it would also suddenly stop working without any warnings. Perhaps my overuse had exhausted it so it staged a strike to express its discontent. The respirator stopped functioning twice in these six years, once in hostel and once while I was outside. Without any indication, it paused. I was totally unprepared for it. It was a test of my ability to breathe and respond.

THE BURNING OF FUSE WHILE I WAS IN HOSTEL

The first incident occurred when I was in my hostel. It was already half-past 10 at night when I finished my assignments. Just as I planned to bathe and go to sleep, the respirator behind my wheelchair let out a “boom”, followed by a billow of smoke and some sparks. It then stopped working. I was shocked. I smelled an intense burning odour and I knew something bad was happening. The respirator must have gone awry. In the past when the respirator broke down, it was because the parts were overused and could not function, and we only needed to replace some parts. A small explosion like this had never happened before. I was worried whether the machine would remain functional. If it had to be written off, it would be an enormous loss. So, I asked my mother to switch the respirator off immediately to prevent another explosion. I also called the 24-hour emergency hotline of the healthcare company to request for a replacement of respirator as soon as possible. But since the company was in Cheung Sha Wan and my hostel was in Tuen Mun, they were not able to come right away to handle the emergency. As the saying goes, “Distant water cannot put out a nearby fire”, I could only rely on myself.

First, I calmed down and told myself not to panic. I concentrated my mind and my strengths on breathing. At the time, I could breathe on my own for over an hour, so I followed my original plan to bathe. I had to finish in 10 minutes in case my breathing worsened. After taking the shower, I stood still

and breathed slowly. I stood behind my wheelchair and grabbed the handles to prevent slipping. I breathed in and out forcefully to keep my trachea open and to avoid wheezing too soon. It was a temporary measure.

My breathing was usually better while standing than sitting, and while sitting than lying on the bed. For that reason, I chose to stand and breathe after bathing to take in as much air as I could. I hoped this could help me to maintain a higher blood oxygen level so I could stay conscious until rescue came and would not faint. Yet after more than 30 minutes (by then it was past 11pm), the staff from the medical company still had not come, and I started wheezing. With no choice, I asked my mother to call emergency services and request the paramedics to come and bring oxygen, to increase my blood oxygen level.

Before the ambulance arrived, I tried to breathe on my own. After a while, I felt my body burning. I was as hot as a man on fire just without any smoke. I kept telling myself to stay calm and not to panic, hoping to make myself more comfortable by breathing smoothly and lowering my body temperature.

The ambulance arrived after about 10 minutes. The paramedics came to my hostel quickly and provided oxygen. Once I wore the oxygen mask, I cooled down and felt better. They also performed a series of checks, connected me to an oximeter to measure my blood-oxygen saturation (SaO₂) and closely monitored my condition. They stayed with me in my hostel and patiently waited for the healthcare company staff to come. But as time passed and the staff was nowhere to be seen, I grew anxious and worried. Seconds passed like years.

The metre of the oxygen cylinder indicated that the amount of oxygen was falling. The amount left could provide oxygen for a maximum of around 20 minutes. Panic and fear set in again and I was unsettled. I did not know what to do. One of the paramedics told me that, for safety, they were obligated to take me to a nearby hospital for oxygen and further treatment if the oxygen in the cylinder was about to be used up. However, I did not want to be

hospitalised. Apart from the complicated and time-consuming admission procedures, my main concern was that the doctors would usually ask me to stay for observation for a day or two, and would not let me leave until they were sure that I was free of anomalies. Staying in hospital was more or less the same as staying in prison. I could merely stare at the ceiling all day long. I could hardly fall asleep either, since the hospital was noisy with so many patients. So, I begged the paramedics to wait for a while longer to see whether the healthcare company staff would come. Fortunately, they agreed to my request.

Several minutes passed and the company staff finally came. He checked my respirator. The preliminary assessment was that the power cables had worn and the fuse had burnt, causing a small explosion. He replaced a new wire and let me try the machine. After about 15 minutes, the respirator resumed normal operation with no problems. He therefore allowed me to continue to use it and decided there was no need for the backup respirator. The paramedics were relieved and left.

THE MACHINE BROKE DOWN WHILE I WAS OUTSIDE

On a morning in December, 2008, my mother, brother and I went to Lok Fu by MTR. We walked from the Lok Fu station to Tung Tau Estate to see a Chinese doctor. As we were about 200 metres away from the clinic, we reached a small slope, and my wheelchair suddenly began diving downhill, and the respirator stopped. About a minute later, it started beeping non-stop.

My brother helped me to reboot the machine but it did not work. We repeated the procedure twice but it made no difference. I knew that it went on strike again. With the experience from last time, I immediately initiated emergency measures. I adjusted the speed of the wheelchair to the highest and rushed to the clinic, stopping nearby. Then, my mother called emergency services and asked for an ambulance to come as quickly as possible to provide oxygen to me to help my wheezing.

Before the ambulance arrived, I kept reminding myself to stay calm. I

counted my breathing. I tried to fully concentrate on my breathing so as to delay wheezing. If I was distracted or started thinking negatively, I would be scared and it would prompt me to wheeze.

In fact, I was terrified. At the time, my health had already worsened. I could no longer stand up to breathe in more air like last time. My neck had also bent backwards, so standing up to breathe smoothly was not possible. Instead, doing so would be counterproductive and increase the chance of wheezing.

There were some external factors which affected my mood and hence my breathing as well. When the Chinese doctor learnt about my respirator problem and that I needed to breathe unaided, she came out from the clinic to see if I was okay. From her face, I could tell she was frightened. She suggested to my mother that, out of safety concerns, I should go to the Chinese medicine hospital of The Chinese University of Hong Kong or the Hong Kong Baptist University to have acupuncture treatment, instead of coming all the way here. She said the universities had advanced facilities which could help me if similar cases happened again. Some of her patients also came out to comfort me and asked me to take deep breaths until the ambulance came. I could see that they were worried, which made me more stressful and distracted me, and I began gasping.

I kept suppressing my anxiety and focused on the rhythm of my breathing, to keep the wheezing under control. I wanted to allay my restlessness, anxiety, fear and horror. I hung on one second at a time.

After about 10 minutes, a paramedic arrived on a motorcycle. He gave me oxygen to ease my wheezing and measured my blood pressure, heart rate and SaO₂, at the same time closely monitoring my physical conditions. Soon afterward, the ambulance also arrived at the scene. Two paramedics took out a tube connected to the oxygen supply in the ambulance and connected it to my mask. I breathed in the oxygen like I was taking the hookah, and I was unable to stop. What the paramedics said were the same as last time, that I had to be sent to hospital if the healthcare company did not show up within

an hour, as the ambulance's oxygen supply would not last for extended periods. The only thing I could do was wait and wait. Yet time passed like flowing water and the company staff still did not appear. This drove me crazy. I did not know what to do, did I really need to be hospitalised?

At this moment, a taxi arrived and a middle-aged man got off. He took out a respirator from his suitcase that was the same model as the one I was using. I was delighted, as I knew rescue had come and I did not have to stay in that cold hospital inhaling pure oxygen mixed with the pungent and disgusting smell of bleach. After he replaced my respirator, I was reborn. I was full of energy and could move around freely without being trapped in that tiny plot of land taking oxygen.

With the two prior experiences, doctors and nurses recommended me to bring a manually controlled air pump when I go out, in case my assistant “goes on strike or throws a tantrum”.

BEING ABLE TO BREATHE IS A DIVINE GIFT

For me, after those incidents, I found that it is God's grace that I am able to breathe. It was not something that can be taken for granted. When I was breathing rapidly or not smoothly, it was like struggling when drowning; I realised how difficult breathing could be. Breathing is the motivation of my life. As long as I could breathe, I would have the courage to face every challenge and continue to fight for my dreams and goals and live a fulfilling life. Thich Nhat Hanh had said, “Breathing is the source of life, and happiness is in the moment.” We need not seek fortunes, it is always with us—it is breathing—we just did not pay attention to it or ignored its existence. Breathing gives energy to all creatures, allowing us to handle our daily activities and work, and it emanates enormous vitality. We should be glad that we can breathe and feel our existence. Being able to breathe is a wonderful, fortunate thing.

VISTING DISNEYLAND

MY FIRST VISIT TO DISNEYLAND

I have been to Hong Kong Disneyland twice since its opening. The first time I went was at its first anniversary. Ten of us, including me, my mother, some relatives, friends and classmates, went together during summer vacation. We travelled from the Sunny Bay MTR station to the park entrance, which took about 10 minutes. The roads were flat so my electric wheelchair moved smoothly. After entering the park, the passages were highly accessible and it was suitable for wheelchairs to go around. I circled the whole park in less than 30 minutes.

I wanted to go to the toilet after lunch, but I could only find the male and female toilets at the restaurant and none for the disabled. I was confused. I asked the staff, they told me that the disabled toilet was located inside the male toilet, but it could only be accessed through the male toilets. That was rather inconvenient for the family members of the disabled who need to take care of them. I hope the park could set up some individual disabled toilets in the future, so that it would be more convenient for the users and would not obstruct the others. It would be a win-win situation.

After that, all of us tried the rides. Since I was sitting in a wheelchair, I was not able to partake in most of the rides, such as Space Mountain, the roller coaster. I could only wait for my mother, auntie and classmate Ming Ming at the exit. With the sweltering sun high in the sky, I was like a dry-steamed *Shumai*, and I almost turned into a “human jerky”. So I drove my electric wheelchair and looked for a cooler place to stay away from the scorching sun. When they went for the Winnie the Pooh Train, I finally mustered up my courage, stood up, sat on the lightweight wheelchair provided by the park and boarded the last cabin of the train. I grabbed the handrails tightly and waited for the train to start. When it moved slowly, the cabin rose and dropped along the uneven rails. At times, I felt the weightlessness. Although my balance was off and I was tossed around, I had lots of fun and felt good.

I continued to try different rides. Buzz Lightyear Astro Blasters was one of them. This game required the players to sit on a train and shoot the targets by laser guns. My classmate, Ming Ming, sat in front of me. My mother and I sat in the cabin behind him. Ming Ming held two guns, and he kept on shooting left and right at the objects around him, and his score soared. I could only shoot what I saw on my right as my cervical vertebra bent to the right and I could hardly see my left side. I was also a bad shooter so my scores only increased slightly. When the train returned to the station, I merely had some 12,000 points. Ming Ming scored more than 200,000 points for each of his guns, making a total of 450,000 points. A huge difference from mine! Yet I thoroughly enjoyed the game. It reminded me of the joy and excitement of the rides I played in Ocean Park years ago.

We all got exhausted and took a rest in a cooler place. Right at this time, the Sleeping Beauty Castle had a spectacular fireworks display. But the roof of where we were located blocked the most beautiful part. I could only see the fireworks falling from the sky. In spite of that, I was watching the fireworks. They were so colourful and bright that they lacerated the black sky and released their light and heat. Then, they slowly disappeared in the sky leaving nothing but a white mist. I suddenly realised that life is like fireworks, which are both so short. If we tried our best to live a fulfilling life, like the fireworks which glowed with light and heat, our lives would not be wasted and we would have no regrets.

After watching the fireworks, we decided to leave. Ming Ming sweated like a “drenched chicken” but he still wanted to play other rides. He was like a child and did not want to leave. We did not want to spoil his fun, so we let him stay and said goodbye. We followed the crowd and orderly left the park.

Once I stepped out of Disneyland and headed to the Sunny Bay MTR station, the control bar of my wheelchair had a red light on, indicating that my wheelchair was running out of battery. This forced me to leave as soon as possible. The time spent in the park was extraordinary and enjoyable. The battery of the wheelchair was nearly consumed. The red light was like a silent protest.

A SECOND VISIT

The second time I visited Disneyland was three years after the first time. It was in the spring of 2009. I had a completely different feeling compared to last time. I did not have much fun and found it not very enjoyable. The reason was that my body had worsened and I now needed to use the respirator for 24 hours a day. I used to use it only when I slept at night. My mobility had greatly reduced so I could not take the rides. What a pity. I could only take part in those which were not vigorous at all, such as watching the parade and dramas. I met an old schoolmate who also needed to sit in a wheelchair in the theatre. We shared our recent activities and chatted a little. We separated after the drama was finished and went on our own ways.

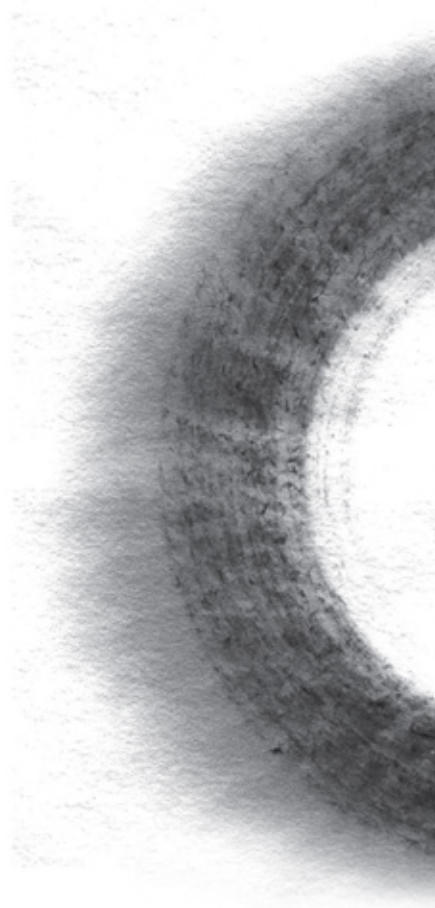
I saw some new amusement rides when I wandered around the park but I could only look at it but not try it. It was somewhat regretful, so I just walked pass them quickly, to not upset myself further. After going around, I chatted with my families and friends, ate a light meal and waited for the fireworks performance at night.

I decided to view the whole show this time. At 7:45pm, we headed to the Sleeping Beauty Castle to look for an advantageous location to watch the upcoming fireworks show. When the hour hand turned to eight, the music began and the fireworks started. The fireworks lit up the whole sky but my attention was drawn to those at the bottom. They were very different from what I saw during Chinese New Year and the Handover Celebrations. They were S-shaped and moved upwards following the castle like tiny silver dragons dancing around the castle. They were extremely bright. Although the fireworks disappeared soon afterwards, I believed their sparkle would stay in the memories of the tourists forever. This was similar to my life. I should be grateful for the abilities I once possessed. Although I had since lost them, I still cherished the good days passed. We should be glad for having owned them, not rue the loss. Because the sparkle is forever. My bad mood dissipated like the fireworks and is replaced with contentedness.



CHAPTER 4

REBORN, PERSEVERE, ASPIRE – MATRICULATION STAGE



REAL JOB APPLICATION, FAKE INCLUSION

In mid-December of 2009, I had my very first job interview. This interview taught me a lesson, but it was also a valuable experience.

In June, I applied for the post of Social Security Assistant of the Social Welfare Department through the government website. But I did not hear any news for several months. Just as I thought it was hopeless, I received the Department's notification letter, asking me to attend an interview in mid-December in Wu Chung House in Wan Chai. I was overjoyed. I started preparing for the interview by collating the required documents and proofs of qualification as well as researching online.

On the day of the interview, I arrived at the interview venue on time. I walked in and saw a few candidates waiting on a sofa. The staff asked me to hand in my ID and academic qualifications documents for checking. A few more applicants gradually joined and they had to give the staff the same documents. From my observation, they all held a university degree and some had more than one diploma. However, the job requirement only requested a minimum level of Form 4. I was shocked. There were so many highly educated people competing for this stable job, from middle-aged job seekers to youngsters to a fresh graduate like me. The competition of Hong Kong society had become so keen, it added to my pressure.

Once I entered the conference room for the interview, the lead interviewer in the middle asked whether I had just finished my study. I answered honestly and said yes. Then, she asked, "Do you know the duties of this job?" I did not expect such a question, I was shocked and stupefied. I calmed down and said, "Processing Comprehensive Social Security Assistance (CSSA) applications, performing home visiting and investigating if there are abuses of CSSA." She was not satisfied with my answer, and added, "You also need to approve the Disability Allowance, provide remedies to the victims of disasters. You may also have to distribute woollen blankets and food to the people in need."

Then, she gave me some cases and asked me to analyse whether the welfare applicants were eligible for financial assistance. After that, I had to summarise the “Four Pillars and Six Industries” concept mentioned in the Policy Address of Chief Executive Donald Tsang and give suggestions to help solve Hong Kong’s wealth disparity. I tried my very best to answer each question. But since she raised so many questions all of a sudden and I had to answer them all in a short time, I felt short of breath.

After she finished, I thought I could take a short break before the next round of questioning began. Yet, her assistants already started asking me how I would enhance CSSA, prevent the abuse of social welfare and so on. I had to answer immediately and without any resting time. They did not stop, they also wanted me to answer some questions in English, such as why was the East Asian Games successful in Hong Kong, did I think it was feasible for the government to organise larger scale sports events, and what improvements could be made.

The interview lasted for some 20 minutes and the interviewers kept on asking and asking endlessly. I had no time to take a breath, think and organise my answers. They were like baseball pitchers and I the batter. They pitched high speed balls and I had to bat the balls one after another, often before I could stabilise myself between pitches. This was extremely exhausting. They did not leave me time to catch my breath, and my breathing became a bit chopping. But I had to answer their questions. Otherwise, they would think that I was impolite, disrespectful and did not know the answers. For that reason, I braced and forced myself to reply. I talked with stammers and I nearly could not utter a sound.

I knew they would not pick me because I could tell from their facial expressions that they were not satisfied with my answers. The lead interviewer told me, only now, that this job involved 24-hour shifts and field services and that my body would not be able to handle these tasks, that they would never consider me. Strictly speaking, it was inconceivable. I was completely knocked out by the interviewers and my confidence for finding work was shaken. This was a great defeat.

In spite of that, I gained a lot from this interview. Firstly, it broadened my horizons and let me understand the importance of preparation. Research about position had to be done before the interview. As I was not well-prepared, I was questioned by the interviewers repeatedly, which finally led to failure. Secondly, it was a valuable experience which taught me about the interview mode of and the questions asked at government interviewers, so I could better prepare. If I had another opportunity to have a governmental interview, I would not make the same mistakes again.

Moreover, this interview made me realise that finding a job was not easy. Seeking a dream job was even more difficult. I had a deeper appreciation of the bitter lives of “employees” and knew more about their difficulties. Most people worked 10 hours a day, some even more, to earn paltry salaries. Often, the money could only support the living of one person, but they had to spend most of their energy and time at work, resulting in insufficient time for entertainment and rest. Isn’t it sad that people have to work like this in our society? If this salary had to feed a whole family, it may be even more inadequate. Does this match with the concept of equivalent exchange? From this interview, I gained a new perspective on the cruelty of reality. I was no longer a naïve student who knew nothing about the world. It was educational.

It is worth mentioning that the government has promoted the idea of inclusion in recent years. It was hoped that the public, especially the employers, would hire more people with disability and give them a chance to make a living on their own. However, I did not see the interviewers consider my physical conditions. I had reported my physical conditions when I applied for this job but I was treated as normal interviewees. I did not have a chance to catch my breath. It was normal to choose the one with the best ability. But shouldn’t the interviewing process be fair to disabled candidates? Shouldn’t opportunity be given to them, to let them show their abilities to impress the employers? I hope the government could take the lead by being more considerate to the disabled during interviews, and by giving them a fairer and more objective environment for them to show their talents and actual abilities.

HONG KONG, CITY WITH NO BARRIERS?

In recent years, the government had urged the public to create a barrier-free city to promote integration between the healthy and the disabled. We all saw the video of Nancy Sit Ka-yin on television promoting barrier-free access and turning Hong Kong into a barrier-free city. Yet in reality, could Hong Kong really become barrier-free? Could the disabled integrate into society? I remain doubtful.

The Equal Opportunities Commission (EOC) had released a report, in which Chairman Lam Woon-kwong said that half of the cases that the EOC received were about disability discrimination, including the design of passageways. As a disabled user, I think Hong Kong still has enormous work to do to create a barrier-free environment and for the disabled to integrate into society. Take for example old districts such as North Point, Sai Wan and To Kwa Wan. As there were no accessibility regulations in the past, the designs of the buildings and public facilities in these districts are outdated. There are no lifts, no ramps or handrails for wheelchair users, and no guiding tiles for the blind. Therefore, it is inconvenient for the disabled to travel in these districts. If a wheelchair user wants to enter a street-level restaurant to have a meal, he cannot, because the step in front of the shop will hinder his access. Nine out of 10 street-level shops have the same design, so wheelchair users have much fewer options. It is not easy to even begin discussing community integration.

For busy districts like Wan Chai and Tsim Sha Tsui, the situation is similar. I went to Wan Chai no long ago and found that most of the restaurants and clothing shops near Southern Mansion had a step seven to eight inches high outside their doors. It was designed to prevent rain water from flooding in and causing the loss of property, but it blocks the access of wheelchair users. There were no barrier-free restaurants nearby either. I could only ask family members to order takeaway and eat it on the street. I still recall how messy it was. If the shop owner would pay a little money to buy and install a ramp, they could already help us wheelchair users. Their sales might even increase. They could kill two birds with one stone, and achieve a win-win situation.

Apart from that, although assistive facilities are present in some buildings and streets, they are often located in remote areas or tucked away. The disabled has to travel a long distance, sometimes passing through twists and turns, to use the facilities. I had been to a shopping mall in Kowloon Bay. I thought I could get to the target floor after taking the lifts twice. However, I saw a few steps of stairs “welcoming” me as I stepped out of the lift. This was shocking. Although there was a small wheelchair lift, the user must first notify the security guards to turn it on to use it. With no choice, I pressed the button and asked security to send someone. After 15 minutes but no one showed, I grew impatient. I called again, telling them that a wheelchair user had been waiting for a while, but still nobody came. I was anxious, but I could only wait on helplessly. After another some time, the security office finally sent a staff to help me activate the lift. The whole process took almost half an hour. It was extremely time-consuming for crossing those few steps. I wondered whether the assistive facilities were set up to help the needy or merely fulfil legal requirements. Maybe they were installed to test the patience of the disabled? Only the commercial buildings’ management would know.

As for public transportation, the assistive facilities on buses and railways have already greatly improved. There are spots for wheelchairs in the compartments to make access easier for wheelchair users. There are also facilities to help them to get on or get off which are very convenient. Yet, on large buses, there is only one “seat” for wheelchairs and it is not enough. Not long ago, my friend and I wanted to go to Sai Kung to visit a friend’s brother at his home. Both of us were on wheelchairs. As each bus could only accommodate one wheelchair, I had to let my friend go first and wait for another bus. That ended up taking around 20 minutes before I got on another bus to Sai Kung. To all bus companies, could you please add more “seats” for wheelchairs, to help us wheelchair users to travel to other districts?

Recently, I read on the newspaper that the EOC had sent officers to inspect 60 public venues. They found steps outside some of the disabled toilets, making them difficult for wheelchair users to access. The toilets were

rendered useless. No wonder Lam Woon-kwong, the EOC chairman, said Hong Kong's pace of promoting barrier-free access was much slower than foreign countries and Hong Kong had ample room for improvement. Hong Kong still has to work hard to become a "barrier-free city" and drive inclusion.



MASTER'S DEGREE ASSISTED BY TEACHERS AND ME

In 2009, when I was still a Year 3 student with one semester away from graduation, I started missing my university life. During these three years, I learnt a lot, I came across a wide range of things and encountered different people as well as matters. However, I felt that what I learnt was too diverse, that I did not have a solid foundation in Chinese literature. I was not “well trained” enough. Hence, I needed to study further. I hoped to expose myself to more aspects of Chinese literature, to learn more and enrich myself. Thus, I had the idea of applying for the master's degree in literature.

It was nearly the end of the semester. Originally, I had planned to apply to the master's degree in September. Then, I could start in the beginning of 2010, and spend half a year letting my body rest and prepare for the hectic courses in the coming two years. But there were two problems to solve first, otherwise, I would not be able to study the master's degree. First, I doubted if my fair results were enough to meet the programme's minimum admission requirements. Second, the tuition fee was some HK\$70,000. With my physical condition, it was nearly impossible for me to find a job. The income of my family was barely enough to feed everyone. There was no extra money left for me to take the programme. Based on these two constraints, I hesitated and dared not to make my decision hastily.

Later, I learnt from my classmates that my results reached the minimum admission requirements. That instantly solved the first problem, and I was relieved. However, the financial difficulty remained hard to solve. I had no way of tackling it myself. But my classmates encouraged me, so I “boldly” told Professor Grace Lau my wish, who was the instructor of both my major and my final year project. Other than guiding me academically, she had helped me a lot in other aspects. Without her, I would not be able to graduate. She was truly my mentor. She was supportive of my decision after hearing about it and urged me to sign up first and wait for the interview. If the admissions board would accept me, we could then discuss about and

tackle the problem of tuition. We may get the school to use its funds and exempt part or all of my tuition fee.

In September, I handed in my application form and the related fees to the office of the Chinese Department as planned. Before that, two or three professors told me that they would help me to pay the fee if the funding from the school would not come. Since I did not want to increase their burdens, I declined their generous offers. Later that month, a professor visited my home. As we chatted, she told me she had already raised the funds needed for the degree course. She handed me an envelope, and said it was the first instalment of the coming academic year's tuition fee of me and my brother. At that time, I did not dare to accept her kindness. I wanted to wait for the results of the interview and my application for the school's funding before making my decision. If funding was approved, I would study the course. If not, I would give up and self-learn at home. I did not want to increase her troubles and pressure as I already owed her too much!

In early November, I received the interview invitation. I attended the interview on time. When I stepped into the interview room, the three teachers who presided over the interview were all familiar faces. Apart from asking some basic questions, like the reasons for choosing this programme and opinions and thoughts on this programme, they spent the remaining time exchanging ideas with me and offering advice. The whole process was like chatting with friends without any stress. It was an enjoyable conversation!

After two days, I was informed by the school that I was admitted after a panel discussion. I felt happy and sad at the same time. I was happy as I received the confirmation and could continue my studies, but sad since I still had not solved the problem of the tuition fee. It was an uncertainty whether the school would provide funding for me so I was perturbed.

A few days after the release of the results, programme director Professor Hsu Tzu-pin called to discuss the issue of waiving the tuition fee. As the semester was going to begin soon, we needed to solve the problem quickly.

He advised me to instantly write a letter to the office of Chinese Department in charge of the master's degree programmes to formally lodge a request for waiving the fee and seek their approval. He would also help me to write a reference letter to brief the school about my situation and propose using the funds to sponsor my tuition fee. So I quickly drafted a simple letter and mailed it to the office the next day. I then waited for their feedback.

After two weeks, I was informed by Professor Hsu that the school had accepted my request. The fee would be waived not just partly but completely. I was overjoyed hearing the news, because I could finally begin my master's studies and was one step closer to my dream. I was so happy my mind turned into turbulent waves. I could not conceal my excitement in the phone. Not knowing what else to say, I said many "thank yous" to Professor Hsu for his tremendous help. I thanked him for contributing so much effort and time to write the reference letter for me and to appeal to the school for the tuition fee exemption, ushering me on my journey of master's studies.

Professor Grace Lau called me afterwards to congratulate me. She told me that 13 professors of the Chinese Department jointly petitioned for my sponsorship, resulting in the school approving full funding for a student's tuition fee for the very first time. I was very surprised as I merely met some of the teachers a few times and I did not take their courses. We really did not know much about each other but they were so supportive and trusting. I am deeply grateful for their support.

BOOK AND SWORD VS. FAME AND FORTUNE

In 2010, I went to two secondary schools to share my life experience with the students. In the Q & A session, the students enthusiastically asked me questions, such as: how do you pick yourself up from a setback, and what would you do if a fly buzzes near you? But I was most impressed by one question: you are trapped in the wheelchair, have you ever thought about giving up your life? I remember this was how I answered the student, “I had thought about it. But not anymore. Although my body is trapped in the wheelchair, my mind is not. It can lead me everywhere; I can be wildly imaginative and go wherever I want. So, I do not think about it anymore.” But why didn’t they ask more about life and death? Did they consider it to be something too distant in their lives, or something taboo or scary?

In recent years, I have pondered over the question of life and death, hoping to find the true meaning of life. Especially these past two years, when some of my friends and schoolmates passed away, my feelings have become mixed. Are humans really so fragile? Why are we struck down so easily by illness? Why is the flame of life snuffed out so easily?

I have undergone two near-death experiences in my life, and both times I cheated death. I have learnt that life is fragile and humans are small, so I want to do something meaningful within my limited lifespan. The values people currently uphold, such as defining a successful life as making a fortune in business or having an outstanding achievement, are not what I would pursue. For me, I now rely on medical devices to survive. Being able to open my eyes and breathe every morning are divine gifts, which always remind me of the importance of health. Money is, of course, important. It can even solve the problems of my medical bills or compensate it. But without a healthy body, it doesn’t matter how much wealth one possesses, is worthless. Thus, making money is not my goal.

As for outstanding achievements, it is trivial to me. What I need to do is succeed in my studies, so that I can make a contribution to society and speak for the helpless and disabled. That is all. Regarding my body, I

have already accepted this “rotten body” because it is impossible to fully recover given the current medical technology. Unless someday, there is a breakthrough in genetic engineering that can repair my damaged and transformed genes. Only then would I have the chance of recovering. But that is just a distant dream.

Just like the old saying, “Live with a book and a sword”, I always aspire to live like the ancient Chinese literati, who, besides studying to increase knowledge, practised swordsmanship and *Wushu*. Apart from training the body, there were bigger purposes, to help the helpless, stand up to injustice and prepare to serve the country at any time, just as the “Immortal Poet” Li Bai. Through reading, I hope to understand more about the world, so that I can be unconfused and fearless, and ultimately conquer the fear of death, or even to face death squarely. I also want to work in a non-profit organisation, to do my best to help others and myself and contribute to society. I think this is the meaning of life.

THE CASE FILE OF NEW DRUG APPLICATIONS

To keep living, find the meaning of life and fight for the right to breathe, when I knew there was a drug that could alleviate and even improve my condition, I decided to apply to the government for using the new drug. In 2010, after submitting our application forms, my brother and I encountered many difficulties and troubles. My mood was up and down during the application process. Sometimes my heart brimmed with mirth when there was hope; sometimes there were butterflies in my stomach when I had bad news, worrying that our applications would fall through. My feelings were mixed. But thanks to the help and support of people from different sectors, I finally saw the light at the end of the tunnel.

The time we submitted the application for Enzyme Replacement Therapy to the hospital was in early September, 2010. Our attending physician and doctor who was responsible for our new drug application performed a series of medical tests on us (blood tests, X-rays, electrocardiograms, 24-hour electrocardiogram examinations, etc.), to collect data for the report that would be submitted to the Expert Panel that would consider our application. The doctor writing the report made it clear to us that the effect of this treatment was significant for early stage Pompe disease patients, that it could improve their physical condition. He therefore asserted that my younger brother would have an obvious improvement after receiving the treatment. But at that time, because I had already been suffering from Pompe disease for 12 years, my muscle cells were already severely damaged. Since no patient in the world using this drug had a condition as serious as mine, it was uncertain whether the treatment could bring improvement. So he was not optimistic about my application. They decided to write the report from a humanistic angle in the hope of moving the members of the Expert Panel to approve my trial of this drug.

Hearing this, nervousness and worry filled my heart. This was the last chance for some of my muscle cells to recover. If my application failed, it would

mean that my body would continue to deteriorate. When my lung function worsened to a certain level, I would need to undergo tracheotomy. A tube would be placed into my windpipe and I would breathe through the tube 24 hours a day. After the surgery, food might also “fall into the wrong duct” when I eat, and probably cause pneumonia. If that happened, I would need a nasogastric tube, so that liquid food could be fed directly to my stomach. I would no longer be able to enjoy the pleasure of eating. If that became true, I could only lay on the bed and do nothing for the rest of my life, and I might as well be dead. Such a situation could easily push someone to the cliff of despair. For that reason, my life hinged on this application. I must therefore strive for this final chance to survive.

To increase the chances of a successful application, while I begged the doctors to write the medical report with an emotional appeal, in the hope of moving the Expert Panel members, I accepted the advice of the Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group. Their PR company would send letters to the media and invite them to cover our case, to galvanise public support and increase the chances of our applications.

Before the media interviews, I tried to, though reluctantly, call my university professors, the vice-principal of Yenching College and some non-profit organisations to ask them to write a letter of support. We hoped the Expert Panel would consider not just the medical data but also humanistic factors and approve our extortionate treatments. I did not expect that they would so enthusiastically respond to our request. Not only did they write the letters and send them to the Expert Panel, some professors even invited their friends to write a letter and solicited the vice chancellor's support. We were encouraged by the enormous support and were emboldened to keep going, to appeal to the Expert Panel to approve our treatment despite public pressure. I am forever grateful to their staunch encouragement and support.

On 24 and 25 November, many journalists from newspapers and TV stations were invited to my home to interview me and my brother. Apart from questions about our conditions, studies, goals, dreams and aspirations,

some of them discharged their journalistic duties and asked us relatively pointed questions. One of the questions impressed me and remained in my mind: “The drug you are applying to the Hospital Authority for is so expensive, it is going to cost millions of dollars a year. It will cost taxpayers a lot of money. How would you plead for their support to let you use the drug? What contribution can you make to the community after using the drug?” It was the same question I have been asking myself. I felt sorry that I was taking so much money from Hong Kong taxpayers’ pockets. I was really ashamed of it. But if we did not do that, our lives were on the line. Caught in a dilemma, I was suddenly inundated with a multitude of feelings. I stuttered with a raspy voice, “We know it will cost the taxpayers a huge amount of money. But we still hope that taxpayers can help us out of a respect for life. If we measure it by how much it costs, we truly have no idea whether we will be able to repay society...” I became emotional. If I did not fight back my tears, I would have burst out crying.

We accepted around 10 interviews in two days. The cameras of the photographers flashed non-stop. I was not used to being photographed this way, plus having to handle the bombardment of questions, I was dazzled, dizzy and exhausted.

Most of the newspapers, magazines and TV stations reported our story on 4 December. Some newspapers even put our case in the news section and found doctors, Legislative Council (LegCo) members, chairpersons of non-profit organisations to comment on the causes, symptoms and development of Pompe Disease. They also ran feature stories analysing our cases in-depth, discussing whether we could regain our health after treatment, as a way to raise public awareness and solicit their recognition and support. All of a sudden, our situations were widely known and became a public focus. My anxiousness had already made it hard for me to fall asleep. Now, with our stories being widely reported and publicly discussed, I felt more pressure on me. I was restless, and more perturbed. Especially when I saw reports of doctors and the medical constituency LegCo member saying that because my condition was too serious, the effect of the drug was questionable. Their analysis echoed that of the doctor who helped me apply for the drug. I felt

dejected and it added to my gloom. I worried about the outcome of the Expert Panel meeting on 8 December. If they rejected my application, I did not know what to do. I was on pins and needles.

After some media covered our stories, other media outlets swarmed in, requesting to interview us at our home. My brother and I suddenly became a focus of media interest. After careful consideration, we decided to go all out, and accepted every interview request to win support from the public and increase the chances of our application. We hoped that we could both receive treatment. But meanwhile, because the journalists desired to know more, especially since they lacked information about my academic performance, they actively sought information to fill in the blanks. They called my faculty office directly to ask for interviews with the professors. I felt deeply sorry for dragging department head Professor Xu Zidong into this, who had to take the interviews to “rescue” me and satisfy their curiosity.

A few days before the Expert Panel meeting, I was worried sick and I was restless. I lost my appetite and had trouble sleeping. I felt I was suspending in the air, anxiously waiting for the Expert Panel to hand down their “judgment” on my brother and me. On 5 December, Professor Grace Lau called me and urged me to calmly accept the outcome, whatever it may be, as we had already tried our best. She also told me that the students of the Chinese Department had created a group on Facebook and initiated a “One person, one Letter to the Chief Executive” campaign, and many people had already joined the group. The Chinese Students’ Society and Students’ Union were also launching a petition on 6 and 7 December to collect signatures and galvanise the support of all Lingnan staff and students. I was astounded. The situation was no longer as simple as I had predicted or imagined. On the one hand, I appreciated the care and support the Lingnan staff and students had given us. They let us realise that my family was not alone in our fight for treatment, that there were many people encouraging and supporting us along the journey. We felt the love in the world. But on the other hand, things were no longer in my control. Our story had become a public issue and a hot button. Even the “Office of the Chief Executive” was involved. I was confused since it might not be a good thing.

On 6 December, the petition at Lingnan University collected more than 700 signatures in one day. It was beyond my imagination. That afternoon, I received a call from Yenching College, the school my brother and I attended for our matriculation courses. Vice-principal Mr Leung said that after reading about our stories in the newspaper, they decided they would write a letter of support on behalf of the college, and launch a petition on 7 December to collect signatures from staff and students to get more support for us. Indeed, the two of us had needed help from teachers and schoolmates all the time in school. We only gave them trouble, without any contribution to the school. And now the whole school was giving us their unwavering support. I really did not know how to repay their immense kindness.

By the evening of 7 December, there were more than 2,200 signatures collected at Lingnan University. The plan was to submit the signatures by hand to the Hospital Authority Head Office the next day to show the staff and students' concern for our application. As for my secondary school, they also collected over a thousand signatures by 6pm. The signatures, along with a letter of support from the entire staff, were given to the PR agency of HKMPS, which would then pass it to the Expert Panel.

That night, I slept poorly. I was very worried about the outcome the next day. Would I be able to endure the failure? Then I thought about what I would do if I really failed. Would I continue the fight? I contemplated this question all night. Rationally, I wanted to just calm down and quickly fall asleep. But my mind would not stop running, thinking about different things. I gradually dropped off when I got too tired thinking.

Around 9am next morning, when I was still groggy, the phone near me suddenly rang. It was Professor Grace Lau. She called me to say some consoling, pacifying words, urging me again to treat the results calmly as she was worried that I could not deal with the failure. She was rushing to the airport to go to Taipei for a seminar. Not wanting worry her, I did not tell her that I was indeed anxious. I kept my negative emotions to myself and asked her not to worry, and quickly ended the call. I got out of bed and had breakfast. But the closer it was to the time of result announcement, the more nervous and stressed I was. I felt a little discomfort, so I laid on the

bed to rest for a while. My heart could not stop pounding. Bum! Bum! Bum! It felt like my heart was coming out of my chest. I almost could no longer bear such great pressure. I quietened my mind immediately so my body and heartbeat would calm down. I even took a nap, without noticing Fruit, my schoolmate, had come.

At around 2pm, the home phone rang. Ring! Ring! Ring! It woke me up. My brother answered the phone. It was the journalist of a TV station, asking if they could broadcast live at our home and the Hospital Authority simultaneously, to know the results at once and interview us about our feelings.

More phone calls came one after another. A few of them were from relatives and friends asking after us and about the latest news. The rest was from the media. They would send journalists to my home for a live broadcast. I hurriedly jumped out of bed and freshened up to wait for their arrival. Around 3:30pm, my home was crowded with journalists and plenty of photography equipment. No fewer than dozens of journalists, most of whom were from TV stations, newspapers and even media I had never come across before, were packed together like sardines in the sitting room. They yearned to know the result. I had never seen such a bustling scene before.

Around 4pm, the journalists had already set up all the photography and recording equipment. Everyone held their breath and waited for the announcement. All of a sudden, the home phone rang. Was it from the doctor? Everybody was listening quietly, but it turned out that it was my relatives sending their regards. They were obviously disappointed. As for me, I was so nervous my palms were sweaty, I also had a little difficulty breathing.

At around 4:20pm, the phone rang again. My brother answered it instantly. Everyone quietly listened to his conversation. It was as if he was receiving instructions, completely unlike the calls from friends and relatives. After about 10 minutes, he handed the phone to my mother. He turned to us and told us that the call was from the doctor, telling us that both of us were permitted to use the new drug, but there were differences in our terms of

using the drug. All the journalists applauded, and the room thundered with hurrah, the cheers enveloping the small apartment. One journalist from a TV station heard the news and began the live broadcast. Within seconds, our faces were shown on the TV screen. Their flashes blinking non-stop. I was stupefied by the news and my mind went blank. I had thought that my application was likely to fail. The doctor, however, said both of us could receive the new treatment. It felt like a dream. We really did it! I heaved a sigh of relief, shedding a load off my mind. All the nervousness and unease built up over the past many days vanished. I was completely relaxed.

Before I could fully digest the news, I already needed to deal with interviews from various media. As my family was busy handling the stream of interviews, Fruit was busy “waiting” on the journalists, pouring tea or water. I was sorry that he, originally our guest, had ended up becoming a waiter!

Around 6pm, some of the journalists left after finishing the interviews. But there were still dozens of them waiting for us. And in the meanwhile, the Chairman of the Expert Panel, Dr. Luk Che-Chung, was on TV talking about the results of our application, and we instantly turned our attention to the TV screen. The news we heard was now further verified, and we could finally be relieved. The journalists in our home left one by one after watching the live broadcast and finishing their job. We thought we could take a break, tidy up and have dinner. Yet, unexpectedly, other journalists came to ask for an interview. The chance of a break vanished. So we kept our wits about us and continued the interviews. At about 8pm, all of the interviews ended and the journalists left. My parents could finally cook dinner and clean the house. As for me, I could also take a break and collect my thoughts.

My emotions this day went on a roller coaster ride. This morning, I was extremely worried that only one of us, or neither of us, could get the permission from the Expert Panel. And I was rather dejected. But by 4pm, when the doctor, who helped us to apply for the treatment, called us during the meeting to tell us that my brother, and I were both sponsored to use the expensive drug, I could not believe it. My mind went blank and I could not readily accept the news. It was surreal. We really got what we fought for, it

was truly a surprise! After suffering for so many years, we finally saw a silver lining. We could finally swagger out of the abyss and into the light.

The success of our application was thanks to the widespread care and support given to us. The application was especially meaningful to me because it gave me a hope of a new life and a shot in the arm, so I could continue to take on the many obstacles to come. The significance of this triumph was more important than Hong Kong Certificate of Education Examination, Hong Kong Advanced Level Examination and master’s degree. It changed my life and made a profound impact.

From now on, no matter how tough the process of treatment would be, I would keep going. Never would I disappoint those who love and believe in me!

DOES THE DRUG WORK? (PART 1)

In December 2010, half a month after we successfully applied for using the new drug, we received a notification from the attending doctor about having health check-ups at the hospital and discussing the treatment arrangements. I received my first treatment at the end of December. Before treatment started, the doctor explained the potential risks to me. I learnt that there were many side effects associated with the drug, the most serious of which included cardiac arrest and dyspnoea, etc. There was also a high level of uncertainty. My feelings were somewhat mixed. I was glad that I could finally try Enzyme Replacement Therapy. There was a chance that my condition would improve, that I could escape from the predicament of continual physical degradation. But I was also worried about the serious side effects that may occur. At any rate, I was not going to give up this valuable opportunity. I was determined to give it a try. I hoped to break out of this “incurable” deadlock and control and improve my disease. So I signed the agreement determinedly and accepted a treatment which was still being tested.

The first time I underwent treatment, the whole hospital seemed like it was “facing a strong enemy”. Doctors and nurses were solemn and apprehensive. The atmosphere was as tense as that of the battlefield. The doctors explained to me that no food was allowed during injection so as to contain the potential danger should side effects occur. His face was strained when he spoke. Yet my mood was poles apart from theirs. I was at peace. I had already decided to try. Even if there were side effects, they were destined and inevitable. I just needed to take it calmly, as being nervous was meaningless.

After inserting a “soy” (Saline Block), I laid on the bed and waited for the drug injection. The doctor told a nurse to take 18 vials of medicine from the pharmacy (50mg in each vial, for a total of 900mg), and extract and mix for the injection. As she returned, the nurse followed the doctor's prescription and extracted the medicine and put it in two saline bags (each one could contain around 400-500mg of medicine). The nurse then hung the bag on the electronic auto-injector, calculated the amount to inject into my body

every hour and input the number for the upcoming injection.

Probably because it was their first time injecting this drug, it seemed that the nurses were in a spin. Repeated mistakes in calculation made them disoriented. But after calculating and reviewing, again and again, they finally got the exact dosage right, and entered the numbers into the injector. It was only then that they had a sense of relief. Given that mixing this drug was complicated and that it might be the first time that the nurses had used it, with no prior experience, the nurses spent nearly two hours to make the medicine and start the injection. Watching them bustling around and getting frustrated over the dosage calculation, I sincerely felt sorry for them.

The injection started at 2pm and ended at 5:30pm, taking a total of three and a half hours. But it was faster than the four hours expected. During the injection, I did not feel any discomfort, so I closed my eyes and slept. My vital signs remained normal and no side effects occurred. The process went smoothly.

Two to three hours after the injection, I still did not feel anything different. My health did not improve. None of the side effects occurred, everything was normal. So I ate some food by myself. Around 9pm, however, I felt slightly hot. The heat was not as high as a fever, only my back sweated. A nurse came to take my temperature and it was still at a normal level. After a while, my palms and feet showed signs of edema. Half an hour later, my thighs sweated profusely like a wet towel. Yet I was afraid to tell the nurse, fearing it would mislead the doctor that side effects occurred. The heating lasted for a while, but then it gradually dissipated and returned to normal.

By noon the next day, while I was waiting for a car to go home, I was hit with a whiff of cold air. My hands chilled immediately. It was supposed to be normal. What was strange was that my hands became warm again a few minutes later—it was swift. This had never happened since my disease's onset. In the past, it would take a long time staying indoors before my hands would warm up, it had never been this fast. I was delighted. Just one injection and it had such a wonderful effect. I felt much comfortable. It was like in

Chinese martial arts novels, where one was “awaken” after the meridians were opened, and now the same was happening to me. I no longer had to be an “ice man” on a chilly day. How could I not be happy when I got this incredible result? Little did I know that three days later, the speed of my body warming up slowed. My limbs were also as frozen as icicles. I felt “reverted to type”. HK\$100,000 just went down the drain. I was cheerful too early.

I recounted what had happened to the doctor at the second treatment. The doctor explained that their aim was to improve my muscle strength rather than for a warming effect. He added that I should not think of the drug as a “miracle cure” that was instantly effective and could make a significant enhancement to my condition. He urged me to be patient and continue the treatment as preliminary effects could only be expected after six months. I too agreed it could not be rushed.

This time, the doctor prescribed one fewer vial of medicine, from 18 to 17. The reason was that I weighed 42.5kg last time. It was supposed to be 2.5kg per shot, and the 18 calculated last time was wrong, the correct answer should be 17. It made me wonder: If I grew heavier later, would the dosage increase? I asked the doctor, but his response was out of my expectation. He said not only was the drug a type of genetic engineering, which was not easy to produce and was in short supply around the world, the cost was very high. Even if my weight increased, they would round up the calculation, and not add a vial because I was 1kg heavier. In my situation, using 17 vials each time was a set quota. Even if my weight climbed, they would still only offer 17 vials to me and they need to use it sparingly.

After this injection, my body did not heat up, nor did my limbs promptly warm up like last time. The “wonder effect” did not happen again. It was a pity. Apart from that, I did not feel any change, not even a slight sense of recovering. I was a bit disappointed.

At the third treatment, the medical staff had become proficient and was not as nervous as the last two times. They even allowed me to eat during the injection.

As it was almost Chinese New Year, the weather had turned cold. To prevent me from catching a cold outside, my mother cut my hair at home to prepare for Chinese New Year. Cutting and washing my hair took approximately 40 minutes this time. Throughout the process, I did not use the respirator, and I did not wheeze. I was amazed. That was the effect of the drug! Compared to the past Christmas holiday, I would lose my breath during the six to seven minutes of washing, especially when my hair was soaked and water rolled down my face, running into my nose and mouth. I needed to ask my father to pause washing to let me catch my breath. At the time, washing was like going to the battlefield; every minute counted, and the fight ended the quicker the better. The goal was for me to go back to my wheelchair as quickly as possible to use the respirator to assist breathing. But it was different now. It was a miracle that I did not need a respirator to help me breathe, that I could do it on my own, for such a “long” time, and I did not wheeze.

Before the fourth treatment, I dialled down the setting of the respirator to avoid getting a “collapsed lung”. When I went to the hospital, I reported to my doctor about the experience of breathing without the help of the respirator. The doctor believed it was a good phenomenon, adding that no anomalies were observed after the treatment. The doctors decided that from this time on, I no longer needed to spend one night in the ward for observation. Also, they inferred that because no side effects were discovered after multiple treatments, the chance that I would develop side effects was low and the risk was not great.

It was good news to me. If I stayed in the hospital, I would hear the noise of different machines all night as well as the footsteps of nurses and janitors. These affected my sleeping and made me languid the next day. It was marvellous that I could leave the hospital after the treatment, go back to my home and have a good night's sleep.

After the treatment, the occupational therapist asked me whether my joints had loosened up. I did not have such a feeling. But in the two months after the treatment, my eating enhanced slightly. The problem of the food “going the wrong way” and causing me to choke no longer happened.

I hoped the drug could help my neck restore some strength, so that it would not bend over backwards. I could then hold up my head, look straight at people, and not just look up to the sky.

I look forward to seeing more patients with similar diseases being able to use this drug. I implore the authorities to consider not just the efficacy and economic benefits when they approve treatment, but make saving lives a fundamental principle, for life cannot be measured with money. It has been proven that these genetic engineering drugs can save the priceless lives of many patients who suffer from genetic diseases.

Furthermore, more patients participating in these medical trials could motivate the pharmaceutical companies and scientists to invest more effort and attract more talent to refine the quality of the drugs and lessen the potential side effects, making it safer for the users. Or it could even be an inducement that could encourage the pharmaceutical companies and scientists to develop a new drug or treatment to eradicate these genetic diseases and cure the patients. My further expectation is that the drug becomes a pill or liquid medicine which could take orally instead of through intravenous infusion. Because the current treatment requires the patients to suffer the pain of injection every two weeks (although it was just a little pain and was not a big deal, it was absolutely not an optimum treatment). I sincerely look forward to seeing the day when medical technology advances to that point where patients would not even need to endure such physical pain. That would be truly beneficial to mankind!



DOES THE DRUG WORK? (PART 2)

PROGRESSIVE TREATMENT

Before long, I had used the drugs nine times. Progress had been generally positive. The most obvious was that my breathing improved. Since using the drugs, I had twice tried having a haircut and a bath without using the respirator. It took about 30 minutes, but I wasn't panting. The strength in my hands also slightly improved. Before, I typed with one hand, while supporting the elbow with the other hand to help it move across the keyboard. Now, I could move freely up and down the keyboard without assistance. Not only that, it had become easier for my arms to lift heavier books. Though I could only hold them for two, three minutes each time before my arms started to tire and hurt, it was still better than the few dozen seconds in the past.

As for my legs, I used to have to hold my thigh with one hand to do the stretching while lying in bed. Now, I no longer needed the "external assistance". What was more amazing was that I no longer needed as much sleep. I used to sleep for 12 hours at night and another two to three hours in the afternoon to get enough energy for my daily activities and work. Now, I just need around nine hours of sleep at night and sometimes none in the day. Or even when I did, only a couple hours were sufficient, and I would wake naturally. So, I had more time for my daily activities.

On the other hand, although there weren't any significant "incidents" during the treatments, there were minor issues occasionally. Quite frequently, the injection machine would stop operating and sound the alarm. This happened around one-third of the time. The reason? After a period of injection, there would be slivers of sediments clogging the filter. This would increase the pressure and the injection machine would automatically pause, stopping the drugs from trickling into the tubs and halting the injection process. The alarm would also go off to alert the nurses, "urging" them to come check on it. This required the nurses to perform some manual operations and do the injection by hand, which increased their workload. The alarm also irked me

and made me nervous and unsettled, and I would become tense and anxious.

Overall, the treatment went well. There weren't any serious side effects and it was a good sign. Just that at the sixth treatment, I dozed off during injection, probably because I was too tired. As I was sleeping, my blood pressured suddenly plunged to the 30s. The nurses woke me up and asked if I felt any discomfort. But I felt nothing abnormal, and the nurse calmed down. The nurse suspected that my blood pressure dropped because I was lying on my side and I was completely stationary. That may have affected the blood pressure.

After the nurse left, my mother said the low blood pressure may have to do with my taking Chinese medicine earlier. Before this treatment, I consulted Dr Chow, someone who I had seen for two years, to see if my lung function had improved after taking the drugs (For safety, I stopped going to Dr Chow for fear that the Chinese medicine would conflict with the Western drugs and affect its efficacy). This visit was to ask Dr Chow to check my pulse and prescribe a week's worth of Chinese medicine for strength improvement. I had finished the Chinese medicine two days before, so theoretically it shouldn't have any effect on this treatment. And yet I couldn't be sure whether this episode of low blood pressure had to do with the Chinese medicine I took. But seeing what had happened, I stopped going to Dr Chow to be absolutely safe.

By the beginning of autumn, I had already received treatment for half a year. I was "one with the drugs" in harmony and it was a good sign. In my latest pulmonary function report, my lung capacity improved, my swallowing became better and I no longer choked while eating, unlike in the past year when I occasionally did. What was even most delightful was that, since treatment started, the settings of my respirator were twice lowered and I could still maintain untroubled breathing. It showed that the drugs were effective.

MY FIRST MEDICAL CONFERENCE

On 15 April 2011, I joined a dinner banquet hosted by a pharmaceutical company as a member of the Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group. The dinner banquet was to host the genetic disease experts and doctors who came to Hong Kong to attend a three-day medical conference.

When I arrived, I saw one of my attending physicians. He was chatting with two foreigners. When he saw me, he came up to me to ask about my condition and how I felt after receiving treatment. From what he told me, I learnt that when he and his colleagues first discussed when to conduct full inspections on us, they contemplated three months or six months. In the end, they decided to do it every half year to allow me to undergo a few more treatment sessions. That way, they could gather more concrete, comprehensive evidence on the treatment's efficacy to prepare for the coming year's treatment application.

I also met HKMPS's Mr Ma at the banquet. Learning that his son had already received treatment for more than a year, I asked what he thought about the injection. I already had syringe holes lined up like a "1" at the back of my left hand that could be clearly seen up close. I found that his son had to go the hospital for injection every week. Due to his son's disease, his hands were short and swollen, making it very difficult for the doctors to locate the veins. So each time it took four to five needling to hit the target. And if the doctor wasn't skilful, it would take six to seven times before drug injection could begin. Yet his son was totally fine about it. Hearing that, I considered myself lucky. I only needed treatment every two weeks, and oftentimes the doctor could hit the target in one go. Compared to his son, I needed to endure a lot less "physical suffering".

Before the banquet began, the president of the pharmaceutical company delivered a speech. He talked about his company's ongoing work in genetic engineering and the company's "grand plans". He said new facilities had been built and they were ready to manufacture genetic drugs, up to two to

three times current capacity. Hearing that, I hoped that more genetic disease patients could benefit from such development and live a longer life. That it would let them see a future and "courageously" stride into life and live out their dreams. (Unexpectedly, after a few months, this pharmaceutical company was bought by another company, so it is uncertain whether the "grand plans" would be affected or would even vanish. That is left to be seen, I only hope that this would not affect the patients.)

The president showed a stack of slides during his speech. One of the slides left a lasting impression on me. It was a before-and-after comparison of a young adult who received Enzyme Replacement Therapy. That person was 18 years old when he started receiving the treatment. He looked depressed; his protruding cheek bones were clearly seen and he was scrawny like a "matchstick man". But after three years of treatment, his appearance was transformed. He looked like a normal young person. He was full of life, and his body—to my surprise—returned to the size of a normal person. Not only did he resume normal weight, his biceps were pumped, even more so than a normal person. I couldn't help but fantasise myself recovering as speedily as he did. It fuelled my imagination and hope for the future.

After the speech, a troupe made a surprise appearance on stage. They performed the classic Cantonese opera excerpt, *White Snake*. As I watched the performance, I realised that all the performers were rare genetic disease patients. I was amazed! Although they were lip syncing to pre-recorded lines, their "move and stance" were quite something—brandishing the spear, waving the flag, somersault—though not exactly dexterous, it was skilful. They never missed a step during the 20-some-minute performance. Their colourful costumes also captured the attention of the audience, who applauded abundantly when the remarkable performance ended. Those overseas doctors and scientists even cheered at such "spectacular skills". To me, I thought that even though their many daily inconveniences hindered their mobility, they strived to do their best with their abilities, and staged a complete Cantonese opera excerpt. With such proof, who is to say they are useless?

SERIOUSLY DISABLED PATIENTS CAN CONTRIBUTE TO SOCIETY TOO

I had originally planned to accept MPS Society's invitation and attend the International MPS Network Meeting in Taoyuan, Taiwan, in late September with my family and other patients and their families. Yet my attending physician was concerned that I may not be able to withstand the cabin pressure and advised me, out of safety concerns, not to travel for the time being. And that I should wait for my health to recover further before making plans. In the end, only my mother and younger brother went to Taiwan to learn about the latest medical developments for MPS. What a pity.

A few days before my mother and brother left for Taiwan, I learnt that the meeting's organiser had invited the "creator" of the enzyme replacement drugs for Pompe disease, Professor Yuan-Tsong Chen and his wife, to attend the conference. What was even more unexpected was that the organiser had also gathered Pompe disease patients of different age groups from the Asia-Pacific region, including Taiwan, Singapore and Malaysia, to attend the conference to share their conditions and healthcare experiences. From what my brother told me afterwards, Prof Chen said a drug developer had developed a new generation of drugs that were expected to produce even better results.

I was encouraged by the news, especially learning that there were other people other than Professor Chen researching treatment. They were willing to spend countless hours refining these unprofitable "orphan drugs" for us patients. Professor Chen, in particular, sacrificed his precious time to collect evidence and advocate different governments to grant their Pompe disease patients drug trials. I am grateful for his charitable deeds, especially since it may end up being "all work and no pay".

My mother and brother also told me that Prof Chen mentioned about an adult Pompe disease patient (in his 30s) in the Philippines, whose condition was more serious than mine, who improved after treatment. Although his condition was quite critical, he never despaired or considered giving up.

On the contrary, he put his keen mind and two movable fingers to use, and operated an online medical equipment trading business. Talk about an impressive intellect! His monthly income was higher than the local average. Not only did he earn a living, he also gave back to society, donating his spare money to the local poor to spread the love. This was another incredible case of the critically sick making contributions to society despite their disease. Apart from admiring him, I was ashamed of myself and for my lack of aspiration. I wondered, when could I make some contributions to society with my paltry efforts? I felt guilty. I knew there wasn't much I could do, I just hoped my words could influence those around me.

LOOKING TO THE FUTURE

Having extended my lease on life after receiving treatment, it is time to plan for the future, doing something I have always wanted to do but couldn't do or dared not to do because of my physical condition. Now that the chance has come, I could try to fulfil my dream.

First, if my health improves in the near future, I hope to travel overseas. My first choice is Taiwan, followed by Beijing. Why these two places? The reason is because they're close by, and there's no need for an arduous journey. Take Taiwan for example. It is only about an hour away from Hong Kong by plane. For Beijing, I can take the train, which takes around 24 hours to go from the Hung Hom train station to Beijing city via the Through Train. I can enjoy the scenery and be spared from the atmospheric pressure on the plane. It is safer. More importantly, there is a power outlet on the train, which I can use to charge my respirator. That's the most important!

Apart from the short distance, another reason I want to go to Taiwan is because I want to meet Professor Yuan-Tsong Chen, director of Academia Sinica's Institute of Biomedical Sciences, in person. I want to learn more about enzyme replacement therapy from him and meet my fellow Pompe disease patients there. I want to see how the treatment has changed their self-care ability and daily life, to gain more comprehensive knowledge on what to expect.

As for the reason I want to go to Beijing, it stems from a recent experience in my classical literature class. I was asked by the teacher about the exact locations of the places I mentioned in my poems, and I couldn't answer. It was so embarrassing! It validated the adage, "It is better to travel ten thousand miles than reading ten thousand books". That's what inspired me to visit landmarks such as the Forbidden City, Wangfujing, the old homes of authors and the Great Wall, etc., to widen my exposure and broaden my knowledge.

Second, I want to focus on my studies after I have recuperated, to get good grades in all subjects and make breakthroughs in my graduation thesis. I want to come up with new ideas, novel, groundbreaking ideas, to broaden myself intellectually and produce a more "focused" thesis, so as not to waste these two years of learning.

Third, I want to get to know more people from different walks of life, to enhance my communication skills and expand my social network. Since I have always had poor health and needed to commute in a wheelchair, I have only been able to take two kinds of transportation: the MTR and the Rehabus. There were also many major activities that I didn't get to attend, such as the annual dinner of the university's Chinese department and the annual general meetings or outings of some organisations. I could only stay at home and read or play video games. I used to believe in the saying, "Knowing the world without setting foot outdoors." But having made blunders in society for years, I realise the saying is only half-true. I know little about society or interpersonal relationships; I am not feeling the pulse of society or getting the chance to interact with others. I don't know how to begin conversing with others nor finding common topics to talk about. I often stutter. My communication skills are really quite poor. Maybe because I'm usually quiet and don't always talk, and I'm afraid of starting conversations, I have missed out on a lot of chances to meet new people. Then, as my mobility declined, I became even more "disadvantaged" in this respect. That's why I really want to make some improvements.

Aside from working, I also want to be able to spare more time to volunteer at NGOs, to meet more people and learn about different things. This is because when I volunteer, I get to meet people from different backgrounds, giving me the chance to talk to them and learn about their lives. That would be like opening books after books of exciting stories. I believe each story is unique. I hope to learn from these stories to complement my own, and caution

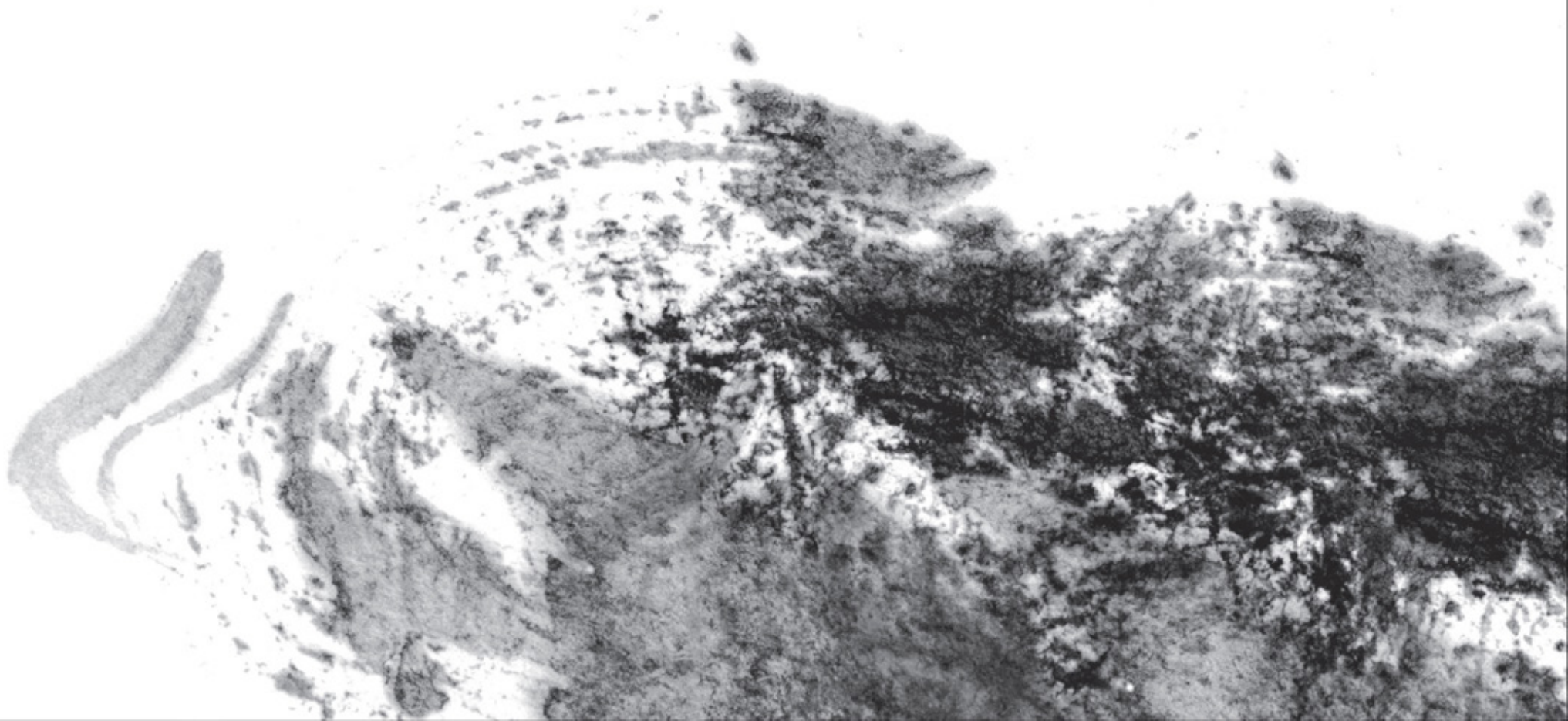
myself not to make the same mistakes that others did. I also want to help others with my meagre efforts, to redirect the love I received to others, so that those who are helpless and mired in difficulties would feel this love. It is better to give than to take. I don't want to just be receiving love and care, I want to be spreading it too; to let those who are suffering to feel it.

I hope to fulfil some of these dreams in the near future. I will strive to make it happen!



PART 2

THE ONES WHO LOVE ME AND
GIVE ME STRENGTH



LIKE A DREAM

I am a very normal, very ordinary person. Like most mothers, I wanted to get married and give birth; I hope my children will grow healthily, work hard at school and become successful with a loving family.

On the day Joe was born, when I woke from the anaesthesia, I was trembling from the pain of the wound. The nurse carried an infant and called my name, asking me to open my eyes to look at my baby. It's boy! My first sight was a healthy baby with a head full of dark hair and nice facial features. He was very cute. But I was confused and sceptical, I had a few questions in my mind. Is this the baby I gave birth to? The child I almost gave my life for? I was worried about the baby's health during my pregnancy and wondered if it would be properly developed. It was because during my pregnancy, I vomited continuously for nearly seven and a half months. But even though I had to endure a painful pregnancy, when I looked at Joe's cute face, I felt it was all worth it. I felt fortunate and happy. It was the joy, happiness and contentment of a new mother.

After Joe was born, my life also started to change. My son became everything, I wanted to give him the best. In kindergarten and primary school, he was often sick with flu, fever and diarrhoea. My husband and I were very worried; we tried to care for his warmth and nutrition as best we could.

Joe had always behaved when he grew up. He had good grades in school. He wasn't the smartest, but he was studious. He received a scholarship in primary school and was once in the elite class. On Parents' Days, teachers and head teachers all praised his conduct, said he was a good child. They were also concerned about his health. If he called in sick, the teachers would call to ask about him, sometimes even teach me what kind of soup to make. I am very grateful to the teachers' kindness. I still remember what they did even after so many years.

Joe and his brother Terry are four years apart. Joe loves his brother very

much. They never fought, and Joe always accommodated his younger brother's wishes. He was a good older brother. He would teach his brother homework and even check his work, relieving my workload as a mother.

When the secondary school places allocation results were released, Joe found that he wasn't assigned to the school he preferred. He was understandably disappointed and upset. The new school required him to take the bus to the terminus and climb almost a hundred steps to reach the entrance. I explained and encouraged him that, "The most important is the school's atmosphere and the teachers. If you work hard, you could still have a good education and get into university." His grades in Form 1 were quite good, he was among the top 10 of his year. From his relaxed demeanour, he seemed happy.

In the second half of Form 1, Joe started to grow. His muscles became firmer and he was stronger than before. He needed larger school uniforms too. As parents, we were glad to see our son grow, and we felt a sense of peace in our hearts. Our family had been living happily together for over a decade; it was a blessing. When Joe reached Form 2, his grades in the first term were also decent, he ranked 27th of his year.

But in the early summer of 1999, just when summer vacation was about over, the nightmare began. Joe had a fever and diarrhoea before the vacation, and it lasted about a week. When he recovered, I made soup for him as always to aid his speedy recovery. But Joe's health didn't improve. Especially when he climbed the stairs, he needed to grab the stair railing to pull himself up, like an old man. The way he walked also became awkward. Joe said his legs felt heavy. As it was about time for the routine paediatric check-up, we asked the doctor then, but the doctor said Joe was fine. I was doubtful. I still felt uneasy by the time we were about to leave, so I asked a nurse about Joe's condition and requested to see another doctor. But she declined. After repeated pleading, the nurse agreed to arrange another doctor to inspect Joe once more. After a detailed inspection, the doctor referred Joe to the Princess Margaret Hospital.

Joe was in and out of hospitals throughout the summer vacation, doing blood tests, urine tests, X-rays, etc. And yet we still couldn't identify what caused his discomfort. On the other hand, I took Joe to the private doctors for inspection. But the doctors couldn't figure out the problem either. My husband and I were worried sick about Joe's condition, and we didn't understand what was wrong. So, we began listening to rumours and became superstitious. We tried and tried and didn't care how much money we spent. We took him to Chinese doctors, Western doctors, bone-setters, chiropractors, doctors who treated rheumatism and even miracle healers. Every night after work, we would take Joe to doctors, we would go anywhere.

Joe was spending more than seven hours at school, and after school, he would go to the doctors, he would queue and wait, end up spending some 12, 13 hours outdoors. After he returned home, he would do homework till 2-3am. He got very little time for sleep. The life of our family turned 180-degrees. Within just three short years, we exhausted our savings, even owing our relatives hundreds of thousands of dollars.

But Joe's health continued to deteriorate. His spine bent and curved some 40 degrees within a year. It compressed his lungs and hindered his breathing. For that reason, he needed a respirator to help him breathe at night. We were agonised by his worsening condition; it was very difficult for us. Our son no longer wanted to go to school. I still had a job then, so my husband and I could only take him to school or pick him up when we had a day off or when we had spare time.

I remember very clearly this one time I took Joe to school. Many classmates at the entrance looked quizzically at the way he walked. When he climbed the stairs, the classmates even separated into two lines and looked on as Joe passed through them. They ridiculed him and said some very bad words. My tears just poured, and my heart bled. By the time Joe graduated from Form 3 after much perseverance, his grades had already dropped to the 90th of his year.

I told the doctors about all of Joe's problems, hoping that they would write to the Education Department and the school. Before Joe graduated Form 3, I

visited the Education Department in person. With the doctor's certification in hand, I requested that Joe be transferred to a suitable school, and I asked the principal to write to the school we chose for an appointment. In the end, Joe successfully transferred to another school for Form 4. The new school had a dozen steps at the entrance, so Joe had to use the backdoor whenever he came to school or left school. The journey home took 15 minutes normally, but for him, he needed 30 minutes, also somebody to carry his backpack for him and hold him as he ambled home.

The new school's Principal Chan, head teacher and classmates all welcomed Joe when he joined. With the teachers' and the classmates' kind assistance, Joe quickly acclimated to the new learning environment. His grades improved by the time he finished Form 4. I would like to take this opportunity to thank the school, the teachers and the classmates for their loving care. Much appreciated!

On 6 August 2001, the doctors performed a spinal fusion surgery on Joe. The doctors said the operation was a complete success. But during the surgery at Queen Mary Hospital, the medical staff mistakenly punctured Joe's aorta, and Joe lost almost 4,000ml of blood. In the end, he needed a transfusion of some 3,000ml of blood. That was already a near death encounter. When he was in the Intensive Care Unit, his throat was clogged by phlegm and he had trouble breathing. When the medical staff tried to remove Joe's respirator, the procedure tormented Joe and again placed him in a critical condition, and he had to be resuscitated by defibrillation. There was also one time when one of Joe's legs felt cold while the other hot. The doctors explained they might have mistakenly hit a nerve and punctured the artery. They had to apologise to my husband and me.

Five days before Joe's operation, I quit my job. I would make soup for him every night after his surgery to help his recovery. At the time, I would leave home at 6am and arrive at Queen Mary hospital at around 7am. I would stay until after 9pm before returning home. This routine lasted about a month until Joe was transferred to a sanatorium.

I decided to take care of Joe around the clock at the sanatorium. I had tried not going home for seven, eight days in a row. Joe later spent an additional two to three months at the Duchess of Kent Children's Hospital at Sandy Bay. So together with his time at home, Joe had spent almost half a year convalescing.

Through a hospital social worker's referral, Joe later enrolled in the Hong Kong Red Cross John F. Kennedy Centre (JFKC) as a boarding student, where he repeated the second term of Form 4 and finished Form 5. I also found a job on Lantau Island. A month before Joe graduated Form 5, he contracted pneumonia and was once again admitted to the Duchess of Kent Children's Hospital at Sandy Bay where he stayed for over a month. Since he wasn't used to the nurses bathing him, I would take the bus from Lantau Island back to our home in Tsing Yi, prepare the soup and food, ride the MTR to Central and take the minibus to the hospital. After bathing him and seeing him finish dinner, I would catch the last minibus to go home. By the time I arrived home it would be almost 8 to 9pm. I would then work on household chores and prepare the food for the following day. Oftentimes, Terry had to make his own dinner and take care of himself.

I was most worried when Joe finished Form 5, because the JFKC didn't offer Form 6 or 7 classes and Joe had to return to a normal grammar school to continue his studies. But I was worried that he was physically unfit to cope with normal school's pace of teaching and that no schools would accept a disabled, wheelchair- and respirator-bound student.

When we were picking schools at the Joint Admission Centre, our first choice was Yenching College, followed by the school where Joe studied Form 4 before. That day, three of us—JFKC's social worker Mr Lo, Joe and I—went to the Joint Admission Centre in southern Kwai Chung to select schools. We were very anxious. When we arrived at the interview room of the school we picked, we saw Principal Chan from the previous school at the corridor. Turned out that the two schools' interview rooms were a wall apart.

I was very happy to see Principal Chan. But I was also embarrassed as we weren't picking his school. After saying hello to him, I introduced myself, thinking he would have already forgotten about Joe. But Principal Chan quickly recalled and asked after us. I said to Principal Chan, "I'm sorry, but I've listed your school as our second choice." But Principal Chan replied, "That's alright, the most important is that the school is good. A school can motivate a student." He added, "Try interviewing next door, if it doesn't work, come back here, I'll take him in, there are still a few places left." I was elated! I thanked him.

Joe and Mr Lo then went into a classroom for Yenching College's interview. As it took place, I clapped my hands together and prayed for a successful interview. Yenching College was the closest to our home and it would be easier for us to take care of Joe. The school was also a "millennium school" and had facilities for the disabled.

Seeing that Joe hadn't come out after a while, Principal Chan also grew anxious. He asked me whether Joe had been admitted and reaffirmed that he still had places available and there was no need to worry. I was once again moved by Principal Chan's kindness and was grateful for his concern. Two to three minutes later, Joe and Mr Lo emerged from the room and Mr Lo announced the good news to me. He said Yenching College had accepted Joe as a Form 6 student, but it was a close call. Before we left, Joe and I thanked Principal Chan again.

When Joe studied Form 6 and 7, he had the loving care of the school, the principal, the teachers, the classmates and the alumni of Yenching College. Everyone looked after him, helping him solve one problem after another and overcome different challenges so that Joe could focus on his studies. I am truly grateful to that. Since Joe had enunciation problem due to his disease, and he suffered from moderate hearing loss, he did not pass his A-Level English exam the first time. He was disappointed he didn't meet the university's entry requirements. But he was determined to try again and not give up so easily. Apart from English, he also decided to retake all the exams.

He decided to repeat Form 7 the day he received the results, knowing that our economic condition wouldn't allow him other academic options. As a mother, I think if his grades could improve, I would for sure support his further academic pursuits. But if his grades wouldn't improve, his academic achievements were passable and should be enough. Many normal people may not even have the chance to finish the entire matriculation course.

I'm grateful that the school allowed Joe to repeat Form 7. That year, Joe's head teacher, Ms Yew, tutored him after class to correct his enunciation problems, training his pronunciation. When the second A-Level exam came, I was worried that if he still could not get into university, he would be devastated. But on the other hand, I was also worried that if he was admitted, how would we manage the tuition fee? On the day the results were announced, Ms Yew called me ahead of the official announcement to tell me the good news. She said Joe's results should meet the university's requirements. I was happy and worried. Joe couldn't sleep the night before. When he heard the news, he was relieved and lightened up. When we arrived at the school, many students were there awaiting the results announcement. It was my second time experiencing this scenario. Some students were excited, some teary, some even crying. It was a hotchpotch of emotions.

When Joe received the results last year, he was visibly distressed. This year, he wore a smile on his face. All the teachers congratulated Joe, even Principal Wong. Joe was very happy and patiently awaited the university admission results. Principal Wong knew about our financial difficulty and offered HK\$10,000 of her own money to support Joe's education. But I couldn't accept her offer.

Principal Wong said, "Once you're in university, you will need to dress better, and there are many things you will need to buy. If you won't accept it, at least take it as a loan. Joe can repay me after graduation when he is financially capable." I sincerely thanked Principal Wong for her generosity and for Yenching College's nurturing over the past three years.

In mid-August 2006, thanks to Lingnan University Professor Grace Lau's

arrangements, I was allowed to move into a dormitory with Joe to take care of him. The dorm had a bedroom and a living room, complete with a kitchen, bathroom and a private room. It was very convenient, as if we had an extra home.

When Joe and I set foot on the Lingnan University campus, we felt relaxed. We were welcomed by an academic atmosphere. As we stepped through the corridors, we saw trees everywhere. The air smelled of flowers punctuated with birds chirping. Magnolia trees, aglaia and herb-like plants lined the road to the dorm.

Through the windows of the dorm, we saw lychee trees, longan trees, banana trees, pine trees and many others I didn't recognise. Every morning and dusk, we could hear different birds and insects. There were also many cats at Block F. One of them was a "big brother" called "Little Tiger", and we often saw mama cat and her kittens.

I used to think that this kind of environment only existed on TV when it portrayed old academies, I didn't realise there was also such a school in Hong Kong. I must thank my son for giving me the opportunity to come here and enjoy this environment.

On Joe's first day of class, I stayed by his side. Things at the university were completely different from secondary school, and that worried me. Part of the syllabus required picking electives, which involved attending lectures. There wasn't a set of textbooks or area of study, and students needed to do their own research. Learning encompassed a wide spectrum of knowledge, and homework often involved voluntarily forming teams with others (at least two persons) to complete the assignments. Joe was disabled, he was not articulate and he was relatively passive. Because of the disease, he would run out of breath after saying just a few sentences. For that reason, he hadn't been socially adept.

At the first tutorial, all the students formed into groups, but not Joe. My heart sunk. After class, I encouraged and consoled him. I said, "Don't worry,

mother is here, I'll help you." At the next class, the tutor said one of the groups had too many people, and wanted to ask one student to partner with Joe. And so classmate Wong and Joe became a group.

Thanks to the tutor's arrangement, Joe was able to tap the classmate's support and assistance when it came to homework. The same voluntary group forming happened at another class. I was again worried that the same would happen and no one would want to team up with Joe. I was on edge. Fortunately, classmate Kong requested to partner with Joe. I was delighted, also very grateful. I was impressed by Kong's courteous gesture. It was a blessing.

For a period after school started, I was worried that Joe's health would not be able to withstand the pressure and that Joe wouldn't be able to finish three years of university. Joe had an older classmate in secondary school, someone who also had muscular dystrophy. He graduated university the same year Joe started. He was, coincidentally, the last occupant of the dorm we lived in. On the day of his graduation, as Joe had to catch up on his homework in the dorm, I went to his graduation ceremony myself. I wanted to congratulate him in person. I was very happy that day. I was touched and I cried happy tears because I thought he was very brave and remarkable to have completed three years of university. Maybe it was also because I shared the feeling as a patient's family. After I returned to the dorm, I shared my experience with Joe to encourage him. I too hoped that he could wear that square cap.

In the first year of university, Joe was still not too used to the curriculum. He gradually adapted after some time and became acquainted with his classmates. The professors, tutors, social workers, janitors, classmates of every class cared about Joe and me. Whenever we entered or left the classroom, the classmates would help to clear the doorway and move tables and chairs away to make it easier for us to pass. I am grateful to all who had helped us, and to the school's assistance.

In Joe's second year in university, although there was as much homework, he was no longer as anxious as in the first year. He must have acclimated to the

environment. He was also studying with classmates like Wong, Kong, Choi, Strong Wrong, Chan and Chow and became close with them. Not only was he no longer anxious, he started enjoying university life. But Joe's health also declined. He would pant easily when he talked and he frequently ran out of breath. When he needed to make a presentation at the tutorial, he could only say a part of his bit and needed other classmates or tutors to help him complete his presentation. But at least it helped him overcome his speaking troubles, and I am sincerely grateful for everybody's help.

In general, Joe was able to cope academically, only that he wasn't physically fit for all his social needs. Since his disease onset, he had participated in few extracurricular activities. That had invariably limited his exposure and worldview, also his life experiences.

I always worried that with Joe's condition, the efforts put in by the teachers, schools and society would be wasted. During his second year in university, my emotions fluctuated while I was troubled by some old ailments; and that affected my son as well, and he became tense. Thankfully, Ms Tam from the school and the professors cared for Joe and me. At Professor Wong's Life and Death Studies class, I also gained a deeper understanding about life.

Graduation neared as Joe entered the third year of university. The three years of university life had given me and Joe a very memorable experience. Our initial worry and anxiousness morphed into satisfaction and joy. The university had given us a stable, free and positive learning environment. And it was the care and encouragement extended by the vice chancellor, professors, tutors, students and university staff that aided Joe's successful graduation. I will forever remember their kindness.

At the graduation ceremony, professors and students ascended the stage and took photos with one another, joyfully celebrating the occasion. I had never had this experience before. I felt I was living in a dream—my son had graduated, really graduated! He was wearing the square cap. I remembered my concerns for his health when he first started university and how long these three years were going to be. But today, all the impossible became

possible, they became a reality. I couldn't express my merriment. Thank you, Lingnan University!

The university had a down to earth atmosphere. Professors and students had a harmonic relationship—they were close, they were teachers and students but also friends, they were like a big family. This atmosphere cultivated a rich learning climate. The students had a sense of belonging. Even for me, every time I set foot on campus, I felt relaxed and comfortable.

After three years of university, Joe felt that he still hadn't learnt enough, and wanted to pursue further education. Yet our financial situation could no longer afford his advanced studies. With the help of Professor Lau and the Chinese department's professors and the dean, the university launched a special fund for Joe to enrol in a master's programme. I want to take this opportunity to thank the university, professors and teachers for their contributions and generosity. My heartfelt appreciation and gratitude!

After Joe graduates from his master's programme, I hope he would repay the university's and the professors' kindness by treasuring what he had learnt and contributing to society.

In 2010, Joe and his brother Terry were able to extend their lives thanks to the Expert Panel that approved the drug treatment, doctors at Princess Margaret Hospital, various organisations, Lingnan University, Yenching College, principals and classmates, and many other parties, also the understanding of the Hong Kong people.

Chau Wai Chung, Mother

MY BROTHER

Until now, there are two people I deeply admire in my life—my mother, a very principled person who always delivers on what she promises; and my brother, a grounded, practical person who does real work, a determined and resilient person.

My brother and I had a harmonic childhood. I don't think I had ever gotten into a fight with him. We never even quarrelled. This is because my brother is more gentle; he would "accommodate" my wishes most of the time and would not "react to force with force". Even if there were sparks, they were quickly extinguished.

When we were little, brother was very quiet. While I would play with other kids in the corridors, brother would stay at home, to study, do homework or watch TV. He wasn't fond of sports. What we did together most frequently was play video games. Our parents bought us a computer when I was in Primary 2—around the mid-1990s—and I would buy CD-ROMs of games to play. Brother would sit beside me and give instructions, or we would play together. Often, we would "collaborate" to finish a game. Later, when there were broadband connection and online games, every time I wasn't free to play I would ask brother to be my "surrogate" and play for me. He rarely refused, maybe he also enjoyed playing!

Brother loves to study, and he works hard. I still remember when we were in primary school, whenever there were dictation or recitation exercises, he would keep repeating the passages under his breath at home. This should not surprise anyone. What was surprising was that he would recite also the punctuation marks, even forming them into a sort of a spell: "comma, comma, comma...". The spells would reverberate across the apartment, incessantly. Of course, this is just a fun anecdote, but it does show brother's zeal and seriousness in his academic pursuits. Compared to my carefree personality, I am no competition!

Brother has always been a beacon for me, shining a light on my path. He is four years older, so I can see my future in him. Especially in primary school and during his transition to secondary school, I witnessed his transformation.

Academically, he taught me what hard work meant. Physically, I saw the changes that came with his growing, and later from his disease onset and doctor consultations. I was nine years old when brother's body started to change. He began having to walk with a stick and became wobbly. After the surgery, he became wheelchair bound and had to use a respirator; later, a heavy-duty respirator and an electric wheelchair. Brother was showing me, step by step, what my future may hold for me. It made me vigilant. Although his experience was cautioning, I didn't want to see his health deteriorate. I didn't want this kind of "witnessing".

I was most impressed by brother's persevering spirit and willpower. His scoliosis surgery was a major operation. Not only did the doctors install steel disks and wires along his entire spine, they also removed some of his muscles. It was an excruciating procedure, yet he endured it without complaint. I didn't get to visit him when he was in the hospital as I had to go to school. After he came home, he never talked about his pain or his painful experience. He was collected and calm, and he quickly realigned his emotions and set out for the future. (According to him, he was despaired and discouraged, just that I didn't notice it.) He ardently caught up with his studies at a special school and even re-entered a normal grammar school to finish his secondary studies and went on to university.

Brother often woke at noon. But sometimes he would wake at 8am but stay in bed reading books and articles. It would be when his stomach started to growl that he would ask us to help him get out of bed. After lunch, he would work for a while and take a nap at around 5 to 6pm. You would think he was tired, but he would read for another while in bed, for about an hour, before falling asleep. At night, he would again do some reading in bed before going to sleep. I have to hand it to him, his love for reading is "beyond words". He really is a "reader"! More importantly, he has an excellent memory. He

remembers most of the books he reads; quite a contrast to my “ability” to “forget at first sight”.

I’m very fortunate to be brothers with him. I hope we could share more experiences together and tread our own paths. But most importantly, we both need to be healthy and happy. If there were another life, I hope to be brothers with him again. But this time we would switch places—I would be the older brother and he the younger brother!

Terry Lai, Younger brother

INFLUENCING ONE LIFE WITH ANOTHER

Joe was a very, very special student I met during my teaching career.

I met Joe at the university admission interviews for two consecutive years. I was glad to enrol him as a student of the Chinese department at the second interview. I had a “selfish” intention at the time: that Joe would teach the students of Lingnan University a lesson about life, that he could use his life to influence other lives.

Many of us would complain even at the slightest ailments like colds or flu. But Joe rarely complained, even though he was most “entitled” to do so. Imagine a lively young person “trapped” in a wheelchair, having to endure muscular dystrophy and the side effects of the drugs and the exhaustion they caused. But Joe didn’t complain. You might think that someone sparse in words like Joe didn’t have an opinion? That would be a big mistake. Joe had strong ideas. In December 2010, Joe and his brother “fought” for treatment using some newly developed drugs. Joe had long had a plan: To fight to survive and wait for new drugs to be developed. How would he give up when drugs were developed but he couldn’t try it? His persistence, his battle for academic achievements during his thorny school years, his fight for the new drugs, all these stemmed from his immense vitality. This young man wasn’t “trapped” in a body with muscular dystrophy, he wasn’t “trapped” in a wheelchair, he was yearning to live.

One life influencing another. Joe also influenced me. I was often tormented and distressed by the little things in life, sometimes losing my inner calm. Yet this young man taught me not to complain or be discouraged by life’s troubles, but to enjoy and be grateful to living. To treasure life; to properly “use” life.

I never thought the “drug trial” incident would send ripples through the Lingnan community. December was one of the two “months of death” for students (the other being April, both were exam preparation months). Some of the students had learnt from the media that the Lai Brothers were deemed

ineligible to use the new drugs and their lives were hanging by the thread. So they started a petition during the “month of death” to gather support for the brothers. I was most touched when one student, who was himself fragile in health, solicited signatures on campus for three days and nights in the chilling December winds. At the time, Joe had already left the university for a few years, and most current students didn’t know him. (Editor’s note: Joe’s master’s programme was part-time. Classes were mostly held at night and he had little chance to meet the undergraduate students.) The students’ enthusiastic response was like the good Samaritan—helping neighbours in need.

As the events unfolded, I had to leave Hong Kong to go to Taiwan to give a lecture, an arrangement made long ago, and so I left with much unease. I thought the “drug trial” had a slim chance to succeed. Just as I was mindlessly having dinner at a Taipei bistro, I received a call telling me about Joe and his brother’s successful bid for the drug trial. I couldn’t contain myself and cheered on the Taipei streets! I was happy for Joe’s achievement and that of the Lingnan students. I couldn’t describe my feelings apart from saying that I was grateful for the blessing. When success seemed improbable, the work by Joe and his family, and that of the Lingnan students and community, turned things around. It was miraculous!

In the beginning, my “selfish” intention was that Joe could teach the students a lesson about life. And look, my wish was fulfilled. More importantly, the subsequent support he received all originated from a pure conscience. This was a precious lesson. Life really can influence other lives!

**Grace Lau, Associate Professor,
Department of Chinese, Lingnan University**

HOPE AND COURAGE—JOE'S SKY

One Sunday morning in November 2010, as I was wandering along a mountain trail in the New Territories (something I rarely did), I received an unexpected call from Joe. I heard a choppy, unclear voice on the other end of the phone. On a normal day, I would already have trouble hearing everything Joe says, as his voice is often strained from using the respirator and he would sometimes heave. It's even more difficult grasping everything he says through the phone. This time, I was far away from the city, and perhaps because the reception was poor, it made it even harder to hear what he was trying to say.

At the time, Joe and his brother were applying to the Hospital Authority to use the new drugs for Pompe disease. Different organisations and media were voicing their support and Joe's family were under a spotlight. Though this was helpful for their application, it inevitably placed them under pressure.

I could hear his angst over the phone; not about the results of the application, but he feared that the organisations and media were disturbing me. "It has become such a big deal and I'm not sure if it's good or bad," he said, his voice sounded as if he was holding back tears. I tried to comfort him, saying that I supported what he was doing because it was right; that even if it affected me negatively, I would still be glad to have done it. I stressed repeatedly, "I'm fine, don't worry", and told him, "At this unruly moment, we could only do our best and not concern about the results. You may think you are fighting for yourself, but you are also fighting for other patients and are indirectly bettering society. It is the right thing to do and you can't be wrong." I urged him to stay calm. That was the first time I felt Joe being so emotional.

When Joe attended my "Life and Death Studies" class in 2008, he caught my attention as he sat at the back of the classroom (to be close to the power outlet) in his wheelchair and breathed with a respirator. His face was so thin and flat that made me wonder if it was the result of being compressed by the

oxygen tubes for a long time. He was wearing a sort of head band to hold his head in position so that it wouldn't drop to the side.

After class, I asked Joe and his mother, who accompanied him to class, about his condition. I learnt that he had Pompe disease, that the onset happened when he was 13 years old, that he had seen many Chinese doctors, bone-setters, acupuncturists, to no avail. With Western medicine, he had done countless tests; but after more than a year, the doctors still couldn't make an accurate prognosis. When he was 15, his spine was bent over 50 degrees, compressing his lungs and causing difficulty in breathing. He did a major operation then, straightening his spine with two metal rods, with smaller horizontal wires to lift his limp body up. "Like a caterpillar," his mother said. Since then, Joe had to sit in a wheelchair. He could move about for short periods of time at first. But gradually, he needed help just to stand up. "A while ago I could halt using the respirator occasionally. Now, I can't afford to leave it even for a moment," said Joe, calmly, as if he was telling somebody else's story. It was hard to read his expression from his face. That was because of the oxygen tubes compressing his face, I guessed.

What surprised me was that in this trying decade, Joe had successfully finished secondary school—even getting decent grades in both the HKCEE and A-Level exams—enrolled into Lingnan University and will soon be graduating. With his abysmal health, I'm certain that he must have invested 10 times more effort and determination than the average person to attain such academic accomplishments. It also showed his persevering spirit.

One time, I invited Buddhist monk Master Liaoyi (了一法師) to speak at our class. Afterwards, Master Liaoyi went up to Joe and talked to him outside the classroom. I listened in on their conversation. Master Liaoyi said, "You and I drew straws in the past. You won, and you came to this world in this broken body. I, on the other hand, came as a monk. We each have our missions. But don't forget the original wish..." I was crying as I listened, but Joe didn't show any emotion on his face. His eyes, however, seemed to look at me in awe, as if saying, "Why are you weaker than me!"

When Joe came to class, he came with his mother and a maid in tow. His mother said she wanted to train the maid to take care of Joe so that she could spare some time and go home to take care of her younger son, who was also diagnosed with the same disease but whose condition was still fine. I later found that this was already the fourth maid they hired. The previous ones all had different issues, either they weren't honest, had a hand injury and could no longer work, etc. One was smarter, but gradually grew tired of the work and let Joe fall for six times—the most serious time leaving a dent in Joe's skull. The new maid had once mistakenly damaged the respirator, and his mother had to urgently get an oxygen mask from the hospital. Joe didn't mention about this serious mistake, yet it left his mother anxious for quite some time.

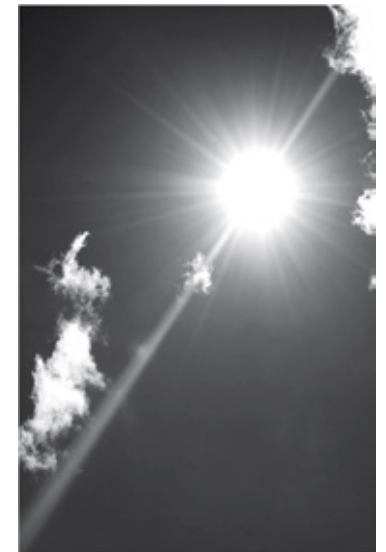
With school, homework and exams, Joe's performance was satisfactory. Although his writing was wavy since his arms lacked strength, I could see his persistence and dedication from his handwriting. He was never late to hand in his homework, and he never handed in half-baked work. This attitude for learning is his attitude for life. Even though he goes in and out of hospitals—sometimes with his life hanging by the thread—Joe never complains, and he never despairs. In one of his assignments, he wrote, “so long as a single breath remains, there is hope”. This shows how he strives to live every day with purpose and in seriousness. He doesn't care about results, only about whether he has given his all. He graduated university with second class honours, and is continuing his master's studies in Chinese literature, a subject he deeply loves.

I invited Joe to write a column for the website of the Life and Death Studies class. I was hoping that he would share his stories, struggles, and demonstrate his resilience and tenderness, his love, hopes, tips in learning and life experiences with others in a conversational format. My original idea for the column was “Joe's Sky”, for the sky is borderless (Tolstoy calls it the “lofty sky” in *War and Peace*) and people can soar freely across the sky, that “Everybody has a piece of sky over their head” (a Chinese adage about everyone having their own destiny) and that Joe has his unique destiny yet he is also marking his own trails in the sky. But Joe suggested using “Hope's

Blog” for the title instead. He wanted to emphasise “hope”, which has guided his journey, led him to overcome his past and overcome his fears. Also, “hope” brings warmth to people's hearts.

There are many things we can learn from Joe. Apart from his refusal to bow down to destiny and give up on his dreams, he also shows us what it means to “live in the moment”. His courage and determination in overcoming difficulties are visible to all. Classmates who know him are deeply affected by Joe's beliefs. It is somewhat ironic that someone who is seemingly powerless has, in turn, made an enormous contribution. This may be what the Tao philosopher, Laozi, referred to as “Do nothing and do everything”.

**Dr Wong Wai Ying, Associate Professor,
Philosophy Department, Lingnan University**



MY STUDENT

Joe and his brother Terry were senior secondary students of the CCC Yenching College. I was the principal at the time. And it has been an honour knowing their family.

Pompe disease has deprived Joe of his muscle strength, caused scoliosis and short breaths, and robbed him of his freedom to move. He is often mired in tiredness, headaches and back pain, and his weight has kept falling. As an ordinary person, it is hard to understand the pain he has suffered. But Joe never complains about it, I only learn about his struggles from his mother.

Joe is sparse in words but he always speaks with meaning. Because he is weak, he has to work harder than his classmates and spend more time in his studies. In his matriculation year, he even won the merit award in the Government and Public Affairs class.

Joe is courteous. He is rarely angry and doesn't feel that the world is indebted to him. When someone helps him, he is genuinely grateful. He is a young man with a keen spirit. If an opportunity presents itself, Joe would capture it and not let go of it easily. He also has plans for his future. He is a remarkable youngster tried and tested by disease.

Joe's condition also brings blessings to those who meet him. When we see him, we would count our fortunes, we would learn to be grateful. Joe's condition has also given us an opportunity to learn. To learn to empathise, to help and to serve.

Joe is also an intermediary, connecting different people and different organisations. Here's one example: In the summer of 2004 after the results of the HKCEE were announced, Joe connected the Education Bureau with a few schools to work together and formulate plans for him. Joe got decent grades at the HKCEE, and he wanted to continue his studies. So, he had to be transferred from JFKC to a normal school. That year, after the results were announced, I got a frantic phone call from a colleague in Kwai Tsing

and from Joe's social worker, hoping that I would enrol Joe. After a series of meetings, Joe decided to attend Yenching College, which was closer to his home.

Joe was the first wheelchair student at Yenching. My school had never had any experience taking care of similar students in the past. For instance, we didn't have desks that matched Joe's needs, so we had to order for one to be made while borrowing one from JFKC. Our staff also worked together designing the desk, to make sure that the table we produced best suited Joe's needs. When Joe shifted to a heavy-duty electric wheelchair, the new wheelchair, along with Joe, became too heavy for the janitors and students to lift on to the stage. The Education Department's Integrated Learning Unit thus acted as an intermediary and borrowed Shatin Tsung Tsin Secondary School's electric stair climber for us. We later bought one which was easier to control and safer to use. If it wasn't for Joe, these organisations may not have the opportunity to work with one another.

Joe's enrolment at Yenching also gave the students a chance to learn to care for people in need. When Joe first used the manual wheelchair, a few of Joe's classmates took turns pushing the wheelchair or helping Joe carry his books. They learnt to help Joe put on his oxygen mask and turn on the respirator in an emergency. I even noticed one quieter male student started talking to Joe and they became good friends. Although Joe had trouble moving, his classmates didn't leave him behind. They even joined different class activities together.

There was one other incident that really touched me. When Joe needed to switch to a heavy-duty respirator, he applied for the Sir Edward Youde Memorial Awards for Disabled Students for a subsidy. Although he received part of the funds, he was still short of around HK\$30,000. The head teacher and I tried to think of solutions. When I told a Ms Lam, a low-profile, down to earth Christian, about Joe's needs, she immediately agreed to sponsor the wheelchair. When she wrote the cheque, she even asked, "Is this enough?" I thought it was the end of the story. When Joe graduated from Lingnan University, I told her the news, intending to let her know that the young

person she helped had done well and graduated university despite hardship. I was surprised when she told me she knew about the news! I knew she had some connections with Lingnan University, but I never thought she kept an eye on this young man and continued to care about him.

Joe's persistence is something for us to model after. He never quit studying due to hardship, and he is almost finished with his master's degree. The most difficult time was probably the exams during Forms 6 and 7. Joe had to answer all the questions within the time given. Yet with his deteriorating muscles, writing was difficult for him. Although the Hong Kong Examination Authority allowed a special arrangement for him, I still found that Joe had strained to meet the time constraints.

We had considered letting Joe answer orally and asking a teaching assistant to write down his answers, but it was difficult for both of them. Joe couldn't speak fluently as he frequently panted. In the end, Joe chose to take the exam with extended time and answered the questions himself. After spending six hours on each paper, I could see he was very tired, to the point of exhaustion. Even though he had to take five subjects and many papers, his handwriting was still well organised. When he had to retake the A-Level exam, he needed to retake only one subject. Yet he decided to retake two for better grades to enter university.

Joe's mother told me Joe was lucky to be able to study at Yenching. The teachers, staff and janitors were all very caring and looked after him. The students and their parents were also nice to him. For that reason, she also arranged for Joe's brother, Terry, to study here. Terry was later elected president of the student association, and I could foresee a colourful and happy school life for him. It must have been a blessing that Joe was able to attend Lingnan University for his undergraduate studies. From what Joe and his mother told me, Lingnan University had been very understanding and caring. They allotted a dormitory to them, arranged the furniture and let Joe's mother attend classes with him. The professors (particularly Professor Lau) also cared deeply about him. I must salute Lingnan University, a human-centred university!

I also want to salute Joe's mother. Not only was she a blessing for Joe and Terry, her contributions and hard work are also commendable and worthy of praise.

May the God lead and bless Joe, Terry and their family, to give them strength and hope to stride into the future!

**Dorothy Wong, Former Principal,
CCC Yenching College**

POMPE DISEASE PATIENTS' PHYSIOTHERAPY

Joe and Terry's disease is the Pompe disease, a rare genetic disease. Patients suffer from a deficiency of lysosomal enzymes that causes glycogen to accumulate, which damages their muscle cells. For the patients, the biggest challenge is progressive muscle weakness and lung capacity reduction.

PROGRESSIVE MYOPATHY

Pompe disease patients will suffer a progressive loss of muscle tissues, affecting the muscles in the torso, shoulders, lower limbs and respiratory organs. With time, the condition will also spread to the upper limbs. Apart from affecting mobility, prolonged muscle weakness will lead to the deformation of the spine and the limb joints, resulting in such impairments as scoliosis, excessive joint expansion and joint dislocation. The lack of muscle stretching may also cause contracture, which increases joint deformation and further affects mobility.

Combating Pompe disease's many challenges is a life-long battle, it requires steadfast determination and perseverance. The therapist is the patient's and their carers' long-term partner. He or she would design suitable exercises based on the patient's physical conditions, lifestyle and living environment, and integrate such exercises into the patient's daily life.

For instance, the therapist has recommended Joe to hold his book up when he lies down to read to strengthen his shoulders and triceps. To prevent Joe's scoliosis from worsening, the therapist has devised back exercises and daily posture improvement routines. As Joe needs to hold on to the railings to enter the bathroom to shower, the therapist has also recommended Joe to perform 10 minutes of standing or stepping exercises while holding on to the railing before taking the shower. The goal of all these exercises is to integrate the therapy regimen into Joe's daily life so that it would be easy for him to follow.

Since the patient lacks muscle endurance, he/she would easily tire after

holding a posture or engaging in an activity for prolonged periods. As such, some cardiopulmonary strengthening exercises are good. For Terry, he could ride the bicycle, take part in aquatic activities or brisk walking. The frequency, weight, duration and repetition of these exercises can be adjusted; and the therapist must fine-tune the regimen according to the patient's continually changing conditions.

In addition, if the patient can maintain muscle elasticity, it can help his/her joint formation, allowing muscles to exert strength in the best position. Apart from encouraging the patient to do stretching themselves, the therapist can also recommend human assisted or equipment-assisted stretching, or integrate stretching exercises into the patient's daily life. For example, to improve Terry's hunching problem, the therapist suggested he spend half an hour lying on his stomach, supporting his upper body with his elbows, while reading or watching TV.

With the progressive physical decline, the patient's muscles and joints will become easily injured or strained. This is just as how Joe's neck and shoulders will become numb or painful after reading or typing for a long time. He therefore needs to balance his activity time and resting time. When Joe encounters mild muscle injury, the therapist would recommend him to rest, apply ice, heat, massage, or electrical stimulation, and use protective gear, to allay the pain and speed up recovery.

When the deterioration makes moving difficult, the therapist could help the patient choose suitable assistive tools, such as wheelchairs, walkers or hoists, and recommend furniture sizes, design and positions to strengthen the patient's movement and self-care ability, maintain the patient's independence at home or in the community and minimise the pressure on the carers. The therapist could also instruct the carers on caring methods, such as changing positions, bathing and feeding, to improve the patient's and the carer's comfort and safety.

RESTRICTIVE RESPIRATORY FAILURE

Patients with Pompe disease often also suffer respiratory failure. The reason is because their stiffened and deformed rib joints and muscular dystrophy cause a significant reduction in lung capacity. Along with short breaths and weak coughs, the patients are often prone to respiratory infections and even pneumonia. As a result, their lung alveoli are collapsed for prolonged periods, causing phlegm accumulation. For the average person, when they cough, there is enough strength in the respiratory muscles and sufficient lung capacity to expel the phlegm or food residue that has accidentally entered the respiratory tract. But the Lai brothers' lung capacity is already minimal, and Joe often has trouble coughing up phlegm, rendering him prone to lung infection.

Since the patient has difficulty inhaling and coughing up phlegm, the therapist will suggest some exercises that could improve respiratory muscles, coordination and techniques, with the aim of maintaining sufficient lung capacity while opening the lung alveoli and exercising the ribs, thoracic spine and shoulder joints. The therapist will also teach the patients relaxing breathing methods, to loosen up the patient's tense neck and shoulder muscles. The patient will practice deep, slow inhaling and exhaling in a comfortable condition and, if necessary, rely on external assistance such as mechanically or manually pressurised airbags to expand the lungs.

The therapist will also guide the patient to perform some breathing and coughing exercises and teach them the correct techniques and postures to cough up phlegm. For patients without sufficient muscle strength, the therapist will teach them specific methods to help them to cough. The therapist may also use postural drainage to clear the patient's deeply trapped phlegm using gravity. If the phlegm is too thick, the therapist may use slaps or vibration to loosen up the phlegm for easier removal. For those who are weak, the therapist will first extract the phlegm using a suction machine and help the patient sit and eat properly to reduce the risk of food or saliva entering the respiratory tract and causing danger.

All in all, therapists can help Pompe disease patients maintain their bodily functions through different trainings and treatments, and to handle the lifestyle changes that different levels of disability bring. They will also care about the carers' pressures and advise caring techniques to enhance the quality of living of the entire family.

As the Lai family and I try to combat the brothers' bodily function deterioration, I have deeply felt what courage and determination mean. I'm confident that we will win this tough battle victoriously.

**Liu Yat-wah, Physiotherapist,
Home-based Rehabilitation, SAHK**

SUPPORTING THE “I WANT TO GO HOME” MOVEMENT

Hong Kong’s mainstream rehabilitation models include the “treatment model”, “individual model” and “social model”.

The “treatment model” defines “disability” as a personal disease or handicap, and rehabilitation focuses on treating the disabled person. The “individual model” defines disability as a lack of individual capacity but recognises the disabled person’s potential. Rehabilitation also focuses on the individual and attempts to enhance that person’s abilities through training and education. The “individual model” can therefore be considered an evolution of the “treatment model”.

However, when it comes to disability created by social structural problems, it is something the government has been silent about. In fact, since the end of the 60s and the beginning of the 70s, many scholars, disabled persons and related organisations have proposed a “social model”, a disability and rehabilitation concept that countered the “treatment” and “individual” models. Under the “social model”, disability and rehabilitation should not merely be considered along the lines of individual impairment, physical handicap or disablement. It should also take into account socio-environmental factors that cause disability, including the environment, social system, economic transformation, social welfare and protection. All these systems, facilities, attitudes that limit and suppress the physically and mentally handicapped are what cause their disability.

The neuromuscular disease called muscular dystrophy is a formidable disease that selectively damages the patient’s limbs, cardiopulmonary functions, speech and swallowing abilities. Since the patient is unable to breathe, drink or eat, they require round-the-clock care. What is most scary is that the patients’ mental capacity isn’t affected, they could only watch their bodies waste away day by day until total paralysis. There is nothing they can do to reverse the situation.

Famed physicist Professor Stephen Hawking is a patient of such neuromuscular disease.

For muscular dystrophy patients, the disease is categorised as progressively degenerative and incurable; patients would never recover physically. To me, rehabilitation can be defined simply as helping the patients to maintain, as much as possible, the standard of living they enjoyed before and to live their remaining days in the community. Yet the Hong Kong government has not properly defined or devised rehabilitation policy for this type of rare disease. As such, current rehabilitation policies lean towards the “treatment model”, without giving regard to the social factors. There is no suitable or effective social welfare system, nor swift assistance; worsening the patient’s disability to the point that they could no longer resume their previous standard of living. Worse, they may even become marginalised.

It is a fact that patients with muscular dystrophy face irreversible body deterioration and inevitable paralysis. Yet why wouldn’t the government provide the appropriate support that these patients need? Sure, medical technology can extend the life of these muscular dystrophy patients, but it can’t salvage their standard of living. After the tracheostomy or gastrostomy surgery, patients need to hire at least one carer to take turns with family members to attend to them 24 hours a day. They also need to rent respirators and many medical devices and buy plenty disposable medical supplies. Conservative estimation puts the monthly spending at HK\$13,000. For an average family, the amount is hardly affordable. Therefore, apart from a disabled body, the disease also brings an economic burden to the patient, subjecting their family to financial strain and greatly affecting their living standards.

For that reason, some patients decide not to undergo tracheostomy for fear of burdening their families and just wait to die. Some patients, after undergoing a tracheostomy, were unable to afford the cost of home convalescence and had to remain hospitalised, separated from their families, even spouses and children. This is a complete departure from the patient’s wish to extend their life to spend more time with their family. For them, the road home is but a fantasy.

At present, the daily cost of keeping this type of patients at the hospital is about HK\$3,000, or about HK\$90,000 a month. Why would the government spend HK\$90,000 on medical costs, but not develop comprehensive and appropriate rehabilitation policies, to help the patients reunite with their families and regain their standard of living? What is even more absurd is that such “can’t return home” situation is happening in Hong Kong, a place with a huge budget surplus.

When muscular dystrophy patients leave the hospital, medical or social welfare agencies do not provide sufficient medical or social welfare support to the patients either. They could at most offer a lump sum fund or suggest the patient’s family apply for Comprehensive Social Security Assistance. They also ignore the special needs and economic burdens of these patients. Most of these patients need to rent the respirators from medical equipment rental companies, and the costs are not one-off expenditures but recurring expenses. The monthly costs can be a great burden for the families. In addition, the government doesn’t provide comprehensive support to the patients’ pre-surgery assessment, rehabilitation or convalescence. Doesn’t this mean that the system can’t even provide the most basic remedy?

In June 2010, the Hong Kong Neuro-Muscular Disease Association (HKNMDA) partnered with Dr Fernando Cheung of The Fortright Caucus and launched a campaign called “I Want to Go Home” to help a group of isolated and resource-deficient muscular dystrophy patients and their families. The aim is to advocate for the special needs of muscular dystrophy patients and appeal for the government’s reasonable response. We also hope that Chief Executive Donald Tsang could make good on his promises in his “So Happy to be Home” promotional video, aired during Lunar New Year of 2010, to fulfil muscular dystrophy patients’ “I Want to Go Home” wish. HKNMDA also launched a never-before-seen “hospital bed” demonstration on 14 November that year to voice their patients’ reasonable demands.

As a social worker who took part in the preparation and execution of the “I Want to Go Home” campaign, my feelings are mixed. I am sad that a group of wheelchair-bound muscular dystrophy patients had to protest with

hospital beds in prosperous Hong Kong. But I was happy to see a group of courageous muscular dystrophy patients and their families go to the frontlines to fight for their needs and those of other patients. I was moved, and honoured to fight alongside them.

Although our “revolution” hasn’t succeeded, we would still carry on, in the hope that our meagre wish for muscular dystrophy patients to go home can be fulfilled. I also hope that Hong Kong’s rehabilitation policy, attitude and environment can be improved. That the government would take effective measures to change, lessen or eradicate the factors that worsen muscular dystrophy patients’ disability, to avoid them from becoming marginalised. Also, to bestow muscular dystrophy patients with sufficient resources so that they can make their own life and death decisions. And collectively respect the value of all lives.

**Sae Sow Jintana, Social Worker,
Hong Kong Neuro-Muscular Disease Association**



THE HIM I KNOW

I'm grateful for the opportunity to talk about Joe in this small corner, and to steal a bit of the limelight in this publication. I've known Joe for only a few years, so I can't say I really know him. My first encounter with him had perhaps happened out of curiosity. I was curious how he, with his broken body, was able to come to this university. Although I too experienced a few turns in my life and barely made it to university, I firmly believe that what I, someone with a healthy body, had done was nothing compared to the pain Joe had to endure.

If we ignored the physique, he is such an ordinary person. Just like people around you and me. He too would feel unsettled, despaired, defeated, and hope to have other people's support and understanding. Like you and I, he would like to chit-chat under the sun. If I must say what is distinctive about him, I would say it's what makes him better than most people—his refusal to accept fate. If I say he has surmounted impediments with his unyielding persistence, would that be an exaggeration? Or is it a fact?

My first impression of him was his seriousness in and dedication to his studies. I still remember working with him on the tutorial report. After discussing the scope of work and the work distribution in the morning, by evening he would have already come up with all the materials. Such efficiency was not just surprising, it made me, someone who wasn't particularly hardworking, feel embarrassed. Maybe it was his "energy". Being so close to death, his insistence on survival gives him an uplifting energy that allows him to look squarely at life, to transcend limitations and to challenge fate. If you're willing to get close to him, you too would feel this vitality invigorating the blandness of life.

He is not articulate. A probable consequence of having been discriminated against that made him reluctant to communicate with others, for fear of getting hurt. There isn't much that I can do for him other than supporting and encouraging him and talking to him, to open up his heart. I'm happy to see his transformation. And I truly appreciate how he cherishes his friends.

Though he isn't always able to express his thoughts clearly (sorry that I complain to you about it sometimes), his care for his friends is apparent, and he has given me warmth whenever I experienced a bad time.

The pressure he has to endure is not minor; especially now that he has successfully applied for the new drug treatment and society is expecting more from him. He is also hoping to make some meagre—perhaps insignificant—contributions to society. I would sometimes worry if he could shoulder such a heavy burden. Are we expecting too much of him? He is not, nor wants to be, the "special one". He just wants to breathe the same air as we do, look at the same sky, live and continue to seek life's meaning.

Do you have someone like Joe around you? Are you willing to be his friend? Please open up your heart and come near him, and listen to his happiness and sadness. The sky is blue and the flowers are blooming. Nature has a way to accommodate everything. For us too, our hearts should be big enough to accommodate such a small, but mighty, ordinary person.

Fruit Kong, Classmate

HIS SOLES ARE NEVER WORN

I met Joe in my first year in university. Both he and I are introverted and shy. Our dorms were nearby, so we acquainted quickly. After Joe graduated from university, he didn't just laze around at home, he has continued his studies and worked hard to complete this book. From penning the manuscript, to repeated editing, to publication, it is no simple feat.

Joe invited me to write a chapter in the book. It took me quite some time to start, as I didn't know how to write my feelings about him. So, I decided to recount some of the things I witnessed. Apart from Joe, his mother is also someone I respect. The hard work and dedication she had to invest in taking care of Joe are not easy for others to comprehend.

Joe is conjoined with his wheelchair and his respirators. He was often seen with his mother on campus. If one stands beside Joe, one can hear his heavy breathing aided by the respirators. Because his lungs are weak, he speaks between gasps and his voice is soft.

Our university classes required oral presentations, and Joe would try his best to participate. He would hold the speech in one hand and the microphone, at a slant, in the other, and he would try to speak quickly. Perhaps he was nervous, he often spoke very rapidly. He would slur sometimes, but everyone would quietly listen on. As I stood next to him, I could only cheer him on in my heart. When his face turned red and he could no longer carry on, his teammates would pick up and continue. But you could always see the disappointment on his face.

He is very serious about his studies. He is always early for class. Every time he needed to hand in a report, he would gather all the reference books right away, and come up with a discussion schedule with his classmates. It was often stressful being Joe's teammate, as he was always so well prepared. I was lazy and happy to muddle along; but his industriousness was always inspiring, reminding me to be more hard-working.

Sometimes when I visited Joe in his dorm, he would either be reading, doing homework or sleeping. It was because he would tire easily after attending a day's class or after reading, and needed to take a nap to regain energy. Now that Joe is studying for his master's degree, the burden of his homework is even greater than before. But he has taken on this challenge resolutely. Our society now places more emphasis on one's educational background than knowledge. So Joe's pursuit of knowledge is admirable.

Joe has difficulty moving about. Although the library is a must-go place for all university students, the lifts can only reach the floor for borrowing and returning books. To reach the floors where books are kept, students need to climb two flights of stairs to the upper floors. When Joe borrowed books, he would usually just tell the clerks the books he wanted so that they would retrieve the books for him, or he would ask for his classmates' help. In fact, there is a lift that can reach the depository floor directly, but he needed to ask the staff to open that door on the third floor that was always closed. Yet he didn't want to inconvenience others, so he rarely went to the third floor.

Over his three years in university, Joe had only been to the depository a few times, to look at rows after rows of bookshelves and a sea of books. The aisles between the bookshelves were very narrow, and his wheelchair could only barely edge into them. Even if he did, it was too difficult for Joe to reach the books. When he went to the library, he would usually just survey the bookshelves and the environment. Spending a leisurely afternoon in the library, sitting on the carpet to read, snatching reference books to prepare for reports, all were a luxury to Joe.

Joe has the support of his family. His mother was by his side all three years of university. In class, Joe's mother would audit the class with us, often even more focused than we were, and she would even jot notes! She also loves to read. When I visited Joe at his dorm, I would often find her lying on the bed reading a novel. After those three years, she could be counted as half an undergrad too.

Joe's mother is very sociable. She would often tell me stories about their

family, from the onset of Joe's disease, their frantic search for doctors and the misadministration of the government, to her finding the new maids unsuitable, she would share the stories with me. I would sense her helplessness, sadness, complaint, but I was not good with words, so I could only share her burden by way of listening. Whenever Mrs Lai talked about sad stories, she would tear up. I didn't know how to console her, and could only mutter some sounds. But I understood the bitterness and greatness of motherhood.

Joe's family is very courteous. Whenever our group of classmates went to his home for the festive celebrations, his mother would often prepare a table-full of food for us, even though they are a family of modest means. Before we went, I would often ask her not to buy too much food, that there was no need. But she would always tell us instead to feel free and eat heartily. After the meals, we would hide some money and call her about it afterwards.

One time, Mrs Lai jokingly complained to me that Joe had thanked many people over the years, just never to her. I responded with a smile. In my mind, Joe is always grateful to the others. He is always embarrassed when he inconveniences other people. How is it possible that he would forget his parents who have given him the most? He is a shy person. It must be difficult for him to say "Thank you" or "I love you" to his mother. There really is no need for gratitude. The very act of living a life of meaning would already be the best way for Joe to repay his parents' love.

Joe's respect for life is admirable. He never complains about the rugged life he has; he just takes it one day at a time. His spirits have never been dampened, rather, he is striding more confidently into the future. Now there is even a beam of hope.

Joe always goes around in his wheelchair. As I look at the soles of his shoes, I see no sign of abrasion. Isn't that just like his spirits? I wish him all the best in the days to come.

Wong Wai Tung, Classmate

IT ALL STARTED FROM “EATING”

I still remember meeting Joe in the second semester of my second year in university. When I first met him, I felt strange. Joe’s mother was always by his side, and I was unsure how to start a conversation with him. I planned to just sneak away after school, but Mrs Lai said, “How about going to the canteen together for afternoon tea?” That was exactly what I wanted. And since there was nothing to lose, I said, “Happy to oblige!”

As we talked over tea, we gradually touched on different topics. Before I realised it, my earlier reservations had disappeared. We talked about anything and everything, from personal stories to anecdotes about our families; almost even the balance of our bank accounts. We became acquainted all of a sudden. This HK\$18 afternoon tea gave me the privilege to join Joe’s ensemble of “meal buddies”, it was perhaps the most “cost effective” afternoon tea I’ve ever had.

Ever since becoming a “meal buddy” with Joe, “eating” has become an indispensable part of our relationship. Mr and Mrs Lai are both of Hakka origins, they’re very hospitable and they like to feast with friends and families. Japanese film director Yasujiro Ozu had loved to film a family eating because the dining table is an epitome of a family.

The Lais are also closely associated with “food and beverage”. Both Mr and Mrs Lai are in the catering business. They had toiled to raise Joe and his brother. To the Lais, eating is serious business and not something to be done sloppily. When I was in university, Mrs Lai would often invite a bunch of schoolmates to Joe’s dorm for dinner. In winter, Mrs Lai would bring out the “earthen pot” and we would happily gather around the table. There was never a shortage of jokes. Although the school is located at a “cold and bitter place”, those of us in the room all felt immense warmth in our hearts.

After graduation, Joe moved out of the dorm and returned home. We “meal buddies” moved with him, and would come to his home for the “Lai’s feasts”. These “family feasts” were far better than the “earthen pot” dinners. Home is

where Mr and Mrs Lai strut their stuff. They would produce six, seven dishes at the snap of a finger. Each dish was colourful, aromatic and tasty. They could turn ordinary ingredients into gourmet dishes.

As someone who sources food for the restaurant, Mrs Lai is adept at her work. Every dish was hearty, and guests would leave happy diners. As Hakka people, the Lai’s “family feasts” always sported Hakka dishes. Signature dishes include Hakka braised pork, salt baked chicken, steamed osmanthus fish and smoked duck; truly foods from “the sea and the sky”. The Hakka cuisine possesses influences of Northern cuisines: they’re rich in flavour and texture. The dishes are like the Lai’s hospitality—lavish in kindness and generous in love and leaves a lingering impression.

Mrs Lai is amiable; she can always strike up a conversation. She loves to share her thoughts and feelings with others. She has strong ideas and rich emotions. Like the dishes she cooks, the flavours are always distinctive. Mr Lai, on the other hand, is more reserved. He is happy to be the listener. He has a good sense of humour; often adding a teasing remark, or a laugh, at just the right moment. The couple complements each other, and they can’t live without the other. They support each other too, and they can read each other’s minds.

The Lai brothers are also like their parents. Joe is reserved like his father; he is shy but thoughtful and composed, and he’s highly analytical. He is also good at caring and understanding others. Laozi once said, “great voices have soft sounds”. The contagiousness of Joe’s silence is very powerful.

In contrast, Terry is more like his mother. He’s lively and active, smart and articulate. He is expressive and can quickly attract attention. The two brothers’ differences—one passive, one active, each with distinctive personalities—have not hampered their brotherly love. Although Heaven has bestowed a disease upon them, the disease hasn’t hindered their free spirit or shimmering lives.

Our acquaintance occurred at just the right moment. If I hadn’t met Joe in

university but a few years earlier, I may have naively ridiculed him like his old classmates and missed a learning opportunity. By the time I entered university, I had already gone through two public exams and grown out of my naivety. This was when Joe appeared as if by divine planning.

During the Warring States Period, there were four princes who were renowned for keeping scholars. I am but a gourmand who tries to fill my stomach with good food. Joe, on the other hand, is the real gentleman. He maintains a steadfast love for life and an insistence on life. I feel a little and ashamed compared to what he has gone through. If I hadn't met Joe, I wouldn't know how to begin reflecting on my life.

Every life is extraordinary. Joe's life is extra-extraordinary. I would never match his perseverance nor would I ever dare to compare myself with him. Yet having met Joe on life's journey, this is already an unregretted life.

Choi, Classmate

