



The Garden in A Hopeless Land

Under the ominous clouds of rare disorders, love shines to transform a withered land into a blooming garden...

ZHENG HUEI CHING

Translated from the Chinese by Avasalu Erik Joseph

This book contains seven stories, recording the journeys of a small group of people.

They have struggled through illness to transform a withered land into a field teeming with life. On their sickbeds, they appreciated life, sought dreams and helped each other. By doing so, they show a colorful world unseen and unknown to the healthy.

They wrote down beautiful poems with their difficult lives.



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A Note from the Author

Warmth

by Zheng Huei-ching

Perhaps I am capable of writing their stories, but I am at a loss when it comes to describing all of the emotional twists and turns they have taken.

They are in fragile boats drifting on the open sea.

Their diseases are like incessant waves that crash down upon them their entire lives. They are pulled wherever the raging tides may take them. During the decades they drift on the sea, every single wave may sink the boat. Fighting for them out at sea are only their loving, strong-willed family members, who cannot bear the sight of their sick loved ones bobbing up and down.

But maybe due to all their hardships, many who are ill now look beyond the storm and accept their fate, no longer struggling nor pleading for help. It is the family members who never give up and do everything in their power to help.

I may have been able to see their faces and hear their cries, but I am merely an onlooker standing on the shore, unable to fully comprehend the fear and panic caused by the crashing waves. And if I am unable to fully understand, am I also unable to response? As an onlooker, is my care and concern confined to the shore, merely able to write what I see?

The only way to truly understand my place in all of this is by spending time with them and not just having scheduled interviews.

I have interviewed a family today, but I have no wish to take any notes. For quite a long time, I have been tired of only gathering information I need. The patients, sitting up or lying in bed, are at peace for the most part and have accepted their fate, even with some timidity. The resounding voices mostly belong to their anxious family members.

For the patients, every interview is a disturbance, and I wonder how tiring it must be for them. But when they agree to see me, they overcome their fatigue and show patience and sincerity. When I actually see them helpless in the hospital and stop trying to solicit information, can I be able to show them warmth as a friend and not a busy writer?

Friendship begins with selflessness and caring for another.

Even if I am unable to give anything, at least I can give a shoulder to lean on. There is no need to say or ask too much; just by being there, one can show warmth and compassion.

Sometimes I cannot help but think when I look at a patient smile: How can I distinguish between a courageous smile and the smile of someone who has given up? How can I understand all their decades of hardship by meeting with them only a few times?

Moreover, I am in the process of drawing boundaries when gathering information about a patient, making it more convenient to organize the data into individual files. I draw these boundaries not only because of time and higher efficiency, but also to escape from reality. I do this because I am afraid of being suffocated—suffocated by disease.

Indeed, the air of disease is suffocating.

I often run away for a while, and come back to continue writing.

I leave, come back...leave, and come back again... When the air becomes too heavy with disease I stop doing interviews, and after mustering enough energy, go back to my work. The work is actually only temporary, and I could quit by yelling out “NO!” if I want to.

This choice to say no is all the difference between the healthy and the sick. For the sick, disease is with them at all times. It is not work but everyday life. Disease is a permanent burden for them. They cannot stop to rest but have to carry it with them for a lifetime.

But I meet with these patients, talk and work with them only at scheduled times. Despite my sincerity, how much better am I than a tape recorder? A-Jie's telephone line knows him better than I do. It listens to him everyday when he talks with other patients far away at the other end about living with multiple sclerosis.

There are times when I reflect upon the nature of my relationship with these patients being so functional, and cannot help but sweat.

In fact, true friendship emerges when we are just there as company without all the interviews and note taking. Li-hua calls to ask where some nice teahouses can be found, Xiao-Xiao sends me a hilarious e-mail, I see Se-meng far off after sneaking away to pay for a coffee... When not face-to-face with them, the warmth of friendship begins to rise up inside. Work is forgotten, and we are simply friends who talk about the happiness and sadness of life. They cease to be patients, and I stop digging for bits and pieces of information. This is when I truly see them and begin to enjoy knowing them.

Remembering the way they look from behind at a distance allows me to slowly understand how the phrase “being functional ” can cut through your heart like a knife.

Is the value of a person measured by how “functional” they are?
Is the value of a life measured by how much benefit a person can
bring to society?

I remember Xiao-hu with whom I talked to a few times over the phone but never met in person. She spoke to me through the receiver from the headset she wore. Her hands were rested on her stomach, because the muscles in her arms had become ossified after thirty years of illness. Xiao-hu had a great sense of humor, and the two of us always had a good laugh over the phone. She was always very tired, however, and politely declined any interviews. Something that left a deep impression with me was when she mentioned an old friend. Her voice stopped suddenly, and then whispered, “She said I was faking it and hiding at home, that I didn't want to go out, competing with others...that I lived off other people.”

Far away from her on the other end of the line, her words pierced right into my heart.

Who was responsible for all the imperfections in life?

Do the healthy and the strong have the right to look down on the sick and the weak?

Xiao-hu passed away in the end. At her funeral, I saw her for the first time—in a picture. She had only been thirty-two years old, and I could see her cheerful smile. But I would never hear that voice again, and I thought to myself, “I wish you happiness and good health in the other world.” Good health was an unfulfilled dream all of her life, and that dream was now completely shattered. I could not stop the tears from streaming down.

After a year of interviews, I rarely witnessed any patient weep openly; it was their family members who did, their sobs covering my

sighs. Facing Xiao-hu's picture with my own tears, I gradually began to mourn, feeling terribly upset and guilty of not having been able to share her burden. I could not help but feel I had lost something, and that nothing could be done. I could never feel her warmth again.

Only after losing her warmth did I begin to feel the warmth of my own tears. I finally realize from what point of view this book could be written. We were now writing it together.

I sit at my desk and stop drawing the boundaries between us. There is no escape for me now, as I begin to write about the life of my friends and the things we talked and cried about.

Acknowledgements

I would like to thank the Taiwan Foundation for Rare Disorders, whose care for people laid the foundation for this book.

I have been greatly moved by the loving heart of friend and founder Serena C. Wu. She once said to me, “We need to give not only medicine to children, but love and patience as well.” In my interviews with patients, I am always careful to remember her words. Foundation CEO Tseng Min-Chieh's words echo in my heart and I dare not forget them, “Peace, justice, compassion, human rights.”

All friends mentioned in this book are a small sampling of the many patients suffering from rare disorders. Whether their real name or pseudonym is used, whether they chose to show their faces or hide them, they have all equally contributed to the writing of this book.

I would like to sincerely thank all those friends who have



searched their painful memories in order to cure me of my ignorance of their world.

You are in a sea of suffering, teaching the healthy what happiness is.

Thank you for sharing your perseverance and showing your strong will to live.

Thank you for speaking out.

Message from the founder

Our Joyful Burden

A Calling to a Life-long Commitment

by Serena C. Wu

We have gone a long thorny road through the storm. Patients of rare disorders and their families have wept together in the darkness for such a long time, I see their scars and hear their cries every day. But from within these shadows, the luminescence of life shines still, and however short or faint it might be, it lights up the future.

I always hoped that someone could write one book concerning such rare lives full of hardship, blood and tears—a book written in a literary style, showing the everyday hopes, dreams, and struggles of this small group. The battles against rare disease have been eternal, so little understood by others, and can happen to anyone. This poses quite a challenge for an author, because the cause is such a mystery.

There are several parties that I wish to thank: I would like to thank the Commonwealth Publishing Group for bravely serving as our publisher in these difficult times. I would also like to thank Ms. Zheng Wei-ho for all her courageous, selfless efforts in making this book a reality. Special thanks go to the author Ms. Zheng Huei-ching for venturing into dark, uncharted waters to search for the secret of the Garden. The breadth of her vision makes it possible to describe the light, warmth and color of life. With fluid prose, she has succeeded in grasping the most truthful, deepest meaning of life at its end.

Over the past year or so, Zheng Huei-ching has gone from doubt

and thinking about giving up, to actively participating in activities held for patients as well as becoming involved in their personal lives. She has interviewed patients with over 10 different illnesses and established close friendships with them, continuously pouring all her observations and care into writing. It seems the work will never be finished, unable to include all the hundreds and thousands of odd disorders in existence, leaving so many people waiting in agony every day, every second. At times, patients cannot wait, their lives winking out like shooting stars in the evening sky. Sometimes it feels like the stories are incomplete, not fully entailing the immeasurable grief and hardships of the yet unresentful caretakers who lead lonely, solitary lives. When a patient named Jin Hu passed away in her youth from Fibrodysplasia Ossificans Progressiva (FOP, which causes muscle to gradually turn into bone), her mother commented on all she had gone through caring for her suffering daughter, paying attention to every last detail to the end. She said, "It was a joyful burden."

It's true! Light and warmth can be found when we meet one another in the sea of illness or because of life's imperfections. Opportunities for limitless freedom can be attained when trying to break through the confines of life and death. Constant tug-of-war with sickness and Death enables people to stick together. The commitment and responsibility of a lifetime is our joyful burden.

●*Serena C. Wu is managing director of the board of the Taiwan Foundation for Rare Disorders. She is also mother to a child afflicted with the rare genetic illness Urea Cycle Disorder.*

Preface by the editor

by Research & Planning Division,
Taiwan Foundation for Rare Disorders

Ever since *A Garden in A Hopeless Land* published in Aug. 30th, 2001, more than 20,000 copies have been sold in Taiwan.

Although *A Garden* only portrays a dozen of patients and their families, their stories reflect in a true and comprehensive way the situation and problems rare disease families in Taiwan may have to face. Therefore, through *A Garden*, Taiwan Foundation for Rare Disorders hopes to educate the general public in Taiwan what rare diseases are and how to support the patients. Since *A Garden* means a lot to the Foundation, we decide to publish an English version to share our experience with a larger community, including fully developed systems and developing ones, and provide better service to rare disease patients all together.

Looking back, we are glad that the patients' lives have been greatly improved through the establishment of laws, including Rare Disease and Orphan Drug Act, Physically and Mentally Disabled Citizens Protection Act, National Health Insurance Act, and The Act of Special Education. Many predicaments pictured in *A Garden* no long exist now. Patients could integrate into the society more smoothly and the society starts to show greater support to them. However, as more and more patients with various diseases need our service, we know we have more tasks to do. We will continue extending our service to all kinds of rare disease patients.

A Garden was adopted into a TV series *Born Fighters*, co-produced by Bureau of Health Promotion of the Department of Health,

and Taiwan Public Television Service Foundation. The TV series was broadcast on Public Television Channel after a year-and-half shooting. *Born Fighters* was the first TV series in Taiwan that featured rare disease patients. Seven case stories from *A Garden* plus the story of Miss Yang Yu-Shin, TFRD's spokeswoman and also a patient of Miyoshi Myopathy herself, made eight touching episodes. *Born Fighters* won two Taiwan Golden Bell Awards for TV in the categories of Best Actress (*Cold Front/ Duchenne Muscular Dystrophy*) and Best Program (*My Stinky Kid/ Urea Cycle Defect*). The actor in episode *Go Across the Overpass, You'll See the Sea*, who starred a Spinocerebellar Ataxia patient even won the Best Actor at Asian Television Festival.

Furthermore, TFRD published *Love is not Rare—A Life Education Brochure*, to accompany the TV series *Born Fighters*, as teaching materials for life education courses in schools across the country. Starting from 2005, there has been a campus tour in order to let university students have better understanding about rare diseases.

For Taiwan society, *A Garden* recorded the long dark history and the light out of struggles with tears and sweats. We will walk with thousands of patient and their families, step by step and hand in hand, out of the darkness into the light.

We would love to share all these with you, and we hope all the rare disease families in the world could embrace the sunshine and lead a life with dignity and happiness.