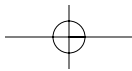


Whose Cross is it to Carry?

Spinocerebellar Ataxia: A Family's Story

This is a story about seven siblings fighting against a dominant genetic disorder. Only the elder sister of the seven did not inherit the gene. Her younger brothers and sisters cope with their disorders through religion and physical therapy, while she has the heavy burden of caring for their mother and six siblings, taking her toll of scars and struggles. Under the wing of this caring hen, the wings of her chicks break one by one. Where is their future? How will this family survive? Their elder sister wants nothing more than create a new dream for her family, to plant a garden...



*The Garden in A
Hopeless Land*



The streets of Taipei, traffic flows like a river. Xia Yan-fen walks unsteadily, having difficulty pushing her sister's wheelchair down a flight of stairs.

“There are obstacles— everywhere— ”

“I hope—we can soon find—a taxi driver who's patient—” stuttered Zhu Ya-pin, Yan-fen's sister.

Their voices were indistinct and dragged out. This was a symptom. Ya-pin had gotten sick first, so her words dragged on and her balance was even worse.

The middle-aged sisters were on their way back home from their weekend chorus group. How were they going to get back, though, was a problem. Yan-fen decided to take her sister home first. After all, Yan-fen could still walk even though she occasionally lost her balance and stepped backwards.

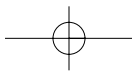
The road was very wide—like the mouth of a tiger. But who would offer their assistance?

Watching them stumble from behind, why was I waiting for someone else? Wasn't I the one who could lend a helping hand to take them home? It wouldn't take too much energy or time, but we tend to wait for others.

Peace for the Soul

The car sped quickly through the city. Things flew by like the little occurrences in our daily lives.

When I first met Yan-fen in spring of 2000, I was struck by her wonderful sense of humor. It made me think being sick only meant bodily discomfort. Only after meeting her siblings, as well as other families after similar tragedies had befallen them, did I realize how ignorant I was of disease.



It was spring when I went to Yan-fen's home for tea.

On a clear, crisp afternoon in her home located in a hillside alley, the light of a desk lamp shone on a Buddhist sutra as Yan-fen chanted. On her shelf were books like *The Heart Sutra*, *What is Chan* by Master Sheng Yen, *The Tibetan Book of Living and Dying*...all of them radiating their respective energies.

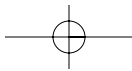
"When you're ill, your body is in a lot of pain. The mind needs something to calm it," Yan-fen said, smiling.

For the past seven or eight years, Yan-fen had frequently attended Buddhist classes and devoted herself to the religion. She and her husband were aspiring to attain a higher level of enlightenment so as to fill the many gaps in her life and ease the frustration caused by her body's degeneration.

Yan-fen became ill about the time she began practicing Buddhism. One afternoon while taking a walk around Sun Yat-sen Memorial Hall, she suddenly lost her balance.

"Finally," she froze and thought, "It has begun. I'm now like my brothers and sisters."

Yan-fen, who worked very hard at her job, was now unable to walk steadily on even ground. Spinocerebellar Ataxia, the rare genetic disorder inherited from her mother, had now begun to grasp hold. She could no longer carry the high-note tunes she sang at her company's annual end-of-the-year party. From this time onward, her situation continued to worsen. Her nervous system lost the ability to smoothly transmit electrical impulses, causing Yan-fen's tongue to function improperly. The hands with which she used to practice her beloved Chinese calligraphy, no longer responded immediately to her will. She had difficulty swallowing, often choked, and felt weak and lethargic.



“I can't fix my eyes on anything—I can't even kill a mosquito, it's so frustrating!” She still went on with a hint of humor: “When my kids were disobedient, I used to kick them with my foot. But now I wouldn't dare try, because I'd fall over first. If I tried hitting them, I'd just be hitting air! Ha-ha.”

On the living room table, Yan-fen prepared a pot of tea and some cups. She prepared to pour, but hesitated and said, “I'm going to spill it.”

She had lost her aim, but not the world. Supporting herself on an umbrella as it were a cane, Yan-fen loved shopping. But she suspected people who saw her coming might think this was a woman drunk or high. Despite her worries, a sense of humor prevailed and she loved making jokes about her illness.

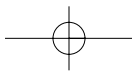
“My tongue doesn't listen to me anymore, and I can't speak clearly on the phone. People think I'm some kind of con artist!”

“Sometimes there are curious people who ask what's wrong with me. My answer is I'm crazy, or at least my nervous system is, hee-hee.”

That's Yan-fen, a devout Buddhist and devout joker, her laugh always echoing throughout the household. She is contented, never feeling sorry for herself, complaining about her illness, nor feeling self-pity for being an adopted daughter. She celebrates her life and religion, grateful for all the love and care her family and friends give.

Connected by an Umbilical Cord

Forty years ago when she was only two years old, Yan-fen was sent to live with the Xia family after her father passed away due to liver cancer. Her foster parents treated her so well that Yan-fen never

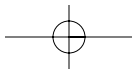


suspected she was adopted, though many non-adopted children suspect they are. When she met her real sister for the first time, Yan-fen noticed the remarkable semblance in their big eyes and high noses, and took her sister for a distant relative. Yan-fen shouted, “Who would have thought that in this world two unrelated people would look so much alike!”

Yan-fen's second year of junior high was the year her birth mother committed suicide because of long-term suffering. Like Yan-fen, her mother had also developed symptoms during her mid-thirties. The Zhu family (Yan-fen's birth family) asked her to attend the funeral. Yan-fen's brothers and sisters whispered in their mother's ear, “Yan-fen has returned to see you.” She had yet to fully realize that this was her true family and birth mother—they had once been connected by an umbilical cord.

“I'm just a little slow in reacting, that's all,” Yan-fen joked about herself. The truth of her relationship with her mother was revealed to her by a relative when she was in college. Since then, she began spending more time with her six siblings.

At Yan-fen's wedding, her brothers and sisters were talking about how their brother Sui-yong was starting to lose his balance. This was the same symptom their mother had, which prompted them to suspect it might be a genetically transmitted disorder. Her mother's side of the family came from Yunnan province in mainland China, so any history of illness in their family was inaccessible. Since there are many mysterious tribes in Yunnan, Yan-fen once wondered if her ancestors practiced some black magic on someone, and that revenge was taken on them in the form of a curse. If she went back to the ancestral home of her mother, would she see a bunch of people stumbling and falling all over the place?



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Was Yan-fen scared knowing that this was a genetically transmitted disorder?

“I wasn't scared, you know, just a bit slow in reacting. And my husband, well, he wouldn't shed a tear unless he were on his deathbed.”

The happy, loving couple had been together for more than ten years and were parents to a young son and a daughter. Her daughter had big, bright eyes like those of her mother. The small girl said, “I'm so happy. My parents never fight.”

Happiness was something tangible in this house.

Yan-fen's husband Li Zhen-fei is a creative director for an advertising agency. He had shot countless beautiful photographs of his family, especially his wife, who was always willing to pose for photographs while they were dating. After getting sick, Yan-fen became much thinner and jokingly said to her husband, “When I leave, you had better use a picture of when I was young and beautiful for the funeral, not any recent ones.”

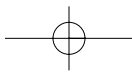
Yan-fen's husband had difficulty coping with these words for some time, but she thought it was funny and kept repeating them. Gradually but slowly, he began to accept the reality they were facing.

“I'm very lucky to have a husband that is willing to face all obstacles with me, to worship with me, and learn how to let go...” She lowered her eyebrows and said, “Otherwise, it would be very heartbreaking.”

Great Responsibility

How can one escape from this deep pain and bitter suffering?

Of Yan-fen's seven siblings, only her elder sister Zhu Sui-ping



had been spared from Spinocerebellar Ataxia.

Yan-fen's courage to face illness and death gave me the wrong impression that the power of one could easily confront such difficulties. Evaluating a situation's severity was never a strongpoint of mine. But after meeting Sui-ping, I not only began to understand the severity of illness, but also discovered the finest quality in people.

Sui-ping played the role of mother in her family, taking on one responsibility after another.

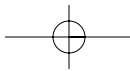
She was only a fifteen-year-old girl when her father died, and her mother's condition deteriorated rapidly immediately afterwards. Her three-year-old brother and two-month-old sister still required care. Sui-ping said goodbye to a carefree childhood, and said to herself in the mirror, "Now I'm head of this household."

She has been unable to rest for forty years since then. Just before one giant boulder crashed down, another started rolling.

Sui-ping married at eighteen, her husband promising to help with the burden of caring for her mother and siblings. The new couple took in the entire big family, but still no one knew the cause of mom's illness.

More than ten years later, not too long after the Zhu's mother had passed away, the oldest son Sui-yong began to get sick. After several doctor visits he was finally diagnosed with "Spinocerebellar Ataxia." The cerebellum, part of the brain that controls bodily movements and balance, would gradually lose its ability to function properly. This was a hereditary disorder passed to the next generation by one parent in the form of a dominant gene, meaning that every child had a fifty percent chance of inheriting that gene.

Symptoms of Spinocerebellar Ataxia usually begin to appear when the person carrying the gene reaches their thirties or forties.



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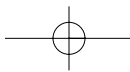
Totally unaware of what the future holds, they grow up as normal children, fall in love, get married, and have children of their own. Wanting to raise a family is a natural instinct, but who could have predicted a storm had been brewing above them? Remembering what happened to their mother when seriously ill, the whole Zhu family was extremely troubled.

Losing Love and Support

Before their eyes, the oldest son of the Zhu family followed his mother in repeating the same events as in her case history. Life goes on, and new generations are born with expectations of a better life. However, hereditary disorders pull them downwards against any will of their own. All one can do is accept it—there is no other choice.

Zhu Sui-yong fell ill at 35, the same age as his mother did. His daughters had just entered elementary school. When he became ill, his entire family's financial burden fell on his wife, and the young daughters were responsible for taking care of their father after school.

Spinocerebellar Ataxia is at its worst during later stages. It begins with the unsmooth delivery of nerve signals and gradually worsens over time. Once only having difficulty speaking and moving, a patient in the later stages of the disorder merely lies in bed, depending on others to help exercise his/her arms and legs. There is a higher likelihood of dying from choking, so the patient must be fed through a tube. This kind of care requires a great amount of energy and skill, which can be very expensive. Lacking support from relatives or the community, members of a core family tend to become resentful towards each another, detrimentally scarring their hearts and minds.



This is what has become of Sui-yong's family. His condition worsened on a daily basis, and his family was in chaos, no longer able to take on the heavy responsibilities of patient care. Sui-yong lost the right to participate in his family's affairs, and was losing their love and support.

Poverty

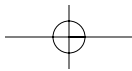
Fortunately there was a guardian angel caring for Sui-yong from afar.

His elder sister Sui-ping had promised their father to take care of her younger siblings. How could she let them fall into a pit of poverty and despair? She accepted this burden and continued taking on the same responsibilities as she had done while caring for her mother all those years. Sui-ping took trips back and forth every weekend from her home in Taichung to Sui-yong's further north in Hsinchu, to help with the cleaning and washing.

This family's destiny was filled with frustration, and Sui-ping often thought about the many sleepless and helpless nights she still must endure, possessing only her own meager strength to rely upon.

She recalled in a teary voice, "Once, I didn't go help him wash his face and brush his teeth for two weeks. He'd been lying in bed the whole time, urinating and defecating all over the bed, it had hardened on his pants, and he was soaked from head to toe on that winter day...He looked at me, crying, and said 'Sis, if you don't take me from this place, I'll die here.'"

These words continued to echo in her mind while on her way back to Taichung. She thought to herself, "His life is in my hands, but how can I take on this responsibility?" After getting home, she talked with her husband about taking in her brother. Her husband



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had shared many difficult years with Sui-ping, but this time he was reluctant to agree. After all, they were just freed of the burden in caring for her mother all those years.

“This is never going to end, is it...,” her husband sighed. “How is it that you’ll never be finished with this for your entire life?”

Your entire life...! With those words, the hard, unsympathetic reality became apparent. She had worked so hard to raise her siblings, to see her own children slowly grow up, and now with the hope of obtaining some of her own space and private time, another giant boulder came crashing down from the heavens.

Giant boulders were piling up, one on top of the other. And now not only Sui-yong was sick, other four siblings began showing symptoms as well.

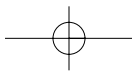
Knowing that Yan-fen practiced meditation and had a supporting family she could depend on, Sui-ping was slightly relieved.

But her sister Ya-pin, who had loving children and a wonderful marriage, became severely depressed after getting sick and suffered from extreme mood swings.

Her brother Ke-ying lost his job and marriage after getting sick, and had no one to rely on but his big sister, Sui-ping.

Another sister Ming-hua was supported by her husband in the beginning. After she could no longer care for herself, however, the medical costs became too high. Without the support of her husband, Ming-hua had no one else to turn to except her big sister, Sui-ping.

Robbed of her own free time and space, her siblings' families gradually falling apart, lack of sympathy and understanding from her own family...Sui-ping was being stretched from different places and suffered several breakdowns. “Don't push me any further,” she would tell her husband with a solemn expression on her face. “If



you do, you'll watch me die before your very eyes!”

Unable to refuse her sick brother, Sui-ping took Sui-yong in without considering the psychological ramifications. Sui-ping lost control on a few occasions, choking her brother, crying, “Let's die together!” Doing so, she revealed how unhappy she was towards her fate, not only due to problems currently facing her, but also a lifetime of being trapped and having no options. After she finished crying, Sui-ping held back her tears and felt the guilt sweltering inside for not having taken better care of her brother.

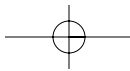
Hardship and poverty thrived on one another.

Sui-ping was a postal worker, and her salary as a lower-level civil servant was limited. Yet there was no end to the care and medical treatment her brothers and sisters required. For several years she wore a uniform during the day, and took it off at night when she became a sidewalk vendor selling beef noodles and dumplings. Alone but strong, she endured. Only she knew that she had psychological problems. There were several occasions when Sui-ping thought of seeking therapy, but at other times she wanted to kill herself along with her brothers and sisters. She was utterly lost—not even religion was a refuge.

“God, it just isn't fair!” Sui-ping had been baptized and was a devout Catholic, but did not step into a church for several years.

Racing Across the Taiwan Straits

Irene Pollin, an American clinical social worker, understands the torment Sui-ping was going through. Irene Pollin's son needs a long-term medical care, inspiring her to become a “Health Crisis Counselor.” In her book *Taking Charge: Overcoming the Challenges of Long-Term Illness*, she mentions how the care-giver



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may become more depressed than the patient':

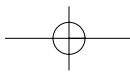
...They [the caregivers] too feel out of control, stigmatized and isolated. They are angry and find themselves challenged. They feel inadequate to handle your care and perhaps your new emotional dependency. They are deeply ashamed because they sometimes wish they could run away from the problem, making you fear their abandonment. The very act of considering the possibility of your death often leads them to confront the idea of their own mortality for the first time...

...Moreover, he [your spouse] may feel ashamed of his feelings and fears. He may believe that you are entitled to be upset but that he isn't. He may feel more isolated than you are and close to burnout. Indeed, if he feels backed into a corner, he may run, which will only exacerbate his negative self-image.

(Irene Pollin, "Taking Charge," pp 37-41)

On top of being the main care-provider for her siblings, Sui-ping is also the only one among her siblings who do not inherit the culprit gene. This exponentially increases the pressure she is under. Despite great advances in gene therapy and breakthroughs in genetic disorder research, there is still, unfortunately, no effective treatment for Spinocerebellar Ataxia.

Bearing witness to the deteriorating condition of her brothers and sisters; admitting that the responsibility for their care could go to no one but her; trying to cope with an insurmountable economic burden—all of this continuously fueled the impulse to head for the inex-



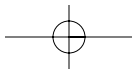
pensive Chinese mainland on the other side of the Taiwan Straits.

In 1993, her brothers Sui-yong and Ke-ying were sent to live with relatives on a farm on the mainland. Though unfamiliar with the proper care necessary for her brothers, relatives could take them out to the fields with the help of wheelchairs while not busy on the farm. This could at least cheer the patients up. Two years later, their sister Ming-hua, whose condition was already quite serious, joined her brothers in this make-do nursing home that required NT\$20,000 per month for the three of them, only one-third of the cost for a Taiwan nursing home. This arrangement greatly lightened Sui-ping's financial burden. But traveling across the straits still proved to have its share of obstacles.

According to mainland immigration laws at the time, Taiwan residents had to leave the territory every three months (their visa could be extended to nine months, the maximum length of stay). The siblings had to be taken to Hong Kong to reapply for their visa, and then take the long train ride back to their relatives' farm. Sui-ping and her youngest brother Ke-qin, who was a heavy-built soccer coach, went through great difficulties taking those trips back and forth.

“Careful planning was necessary every time—when to take a plane or when to squeeze onto a train, because it would cost about NT\$200,000 for one trip. If we weren't careful with money, we wouldn't have been able to get by,” Sui-ping sighed.

Sui-yong's last trip was onset by an expired passport, which required him to travel back to Taiwan to apply for a new one. Knowing that little time remained, all he wanted was to return to his own home. He felt utterly helpless when his wife refused. Sui-ping comforted him over the telephone that she would let him stay at her



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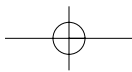


place in Taichung for one week before going back to the mainland. Sui-yong knew now that he could never go home again, and thereby lost his will to live and refused to eat. After seeing his sister for the last time, he passed on. His body had been covered with pressure sores from lying in bed so long.

Upon seeing her brother's horrid, final state, his skin cracked or peeling all over his body—a sight no individual could bear to lay their eyes upon—Sui-ping, even though she loved him very much could not help but say to God, “By letting him pass away, You have relieved him of so much suffering.”

While Sui-yong was in the process of being cremated, Ming-hua contracted pneumonia and had to be admitted to the hospital. Sui-ping had to handle her brother's funeral arrangements and attend to her sick sister in the mainland, while hiding her grief from her other siblings in Taiwan. In 1997, she said that it was lonely holding on by herself. Carrying a backpack with her brother's ashes inside, she boarded the airplane going back to Taiwan, and said, “You wanted to go home. Now I'm taking you home.”

Impermanent is the nature of life. Her brother's death taught her to open her eyes and see beyond suffering, to see the good things in life. However, at the opening ceremony of the Spinocerebellar Ataxia Association in the summer of 2000, she broke down in tears while telling her brother's story. She spoke about how Sui-yong had never received the respect and dignity he deserved, how difficult it was for him to do things on his own, and how her brothers and sisters lacked adequate nursing home care. “My brother, he—literally rotted to death!” Upon hearing her poignant story, the hundreds of people in the audience could not help but be moved to tears and wept with her.



How much longer will families affected by genetic disorders have to bear this pain?

How much longer can one person carry on the burden of this tragedy?

Carrying the Cross for Genetic Disorders

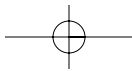
Not long after Sui-yong had passed away, Sui-ping brought Ke-ying and Ming-hua back to Taiwan.

But something heartbreaking was about to happen. Ming-hua had once again been admitted to Taipei Veterans Hospital due to pneumonia and was in critical condition. More bad news was broken to Sui-ping as she was busily attending to Ming-hua: Ya-pin had tried to commit suicide!

Once full of life and an absolute knockout who could turn any man's head, Ya-pin had still kept her charming and straightforward personality. Even though her hands and feet were unsteady, she would insist on fumbling for her keys and opening the door by herself so as not to trouble anyone else. She had strong integrity, but gradually lost touch with old friends. Whenever Ya-pin heard them talking about what they did for fun or where to travel, it not only depressed her, but also made her realize it was becoming ever more obvious that they were now living in different worlds.

Ya-pin became severely depressed after being sick for a few years. Sui-ping was even more prone to panic now, despite the fact her sister's suicide attempt had failed. Under the wing of this caring hen, the wings of her chicks broke one by one. Where is their future? How will this family survive?

Pacing back and forth and sensing the end had come, a ray of faith emerged from deep in her heart.



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Sui-ping went to the Catholic chapel within the hospital, intending to obtain a small picture of Mary and place it at Ming-hua's bedside so that her siblings could pray when visiting. The chapel door was closed, however, and Sui-ping instead found a card left by the Franciscan Sisters. There was an inscription written on the top, which read: "If you are in need of a prayer or require help, please write us."

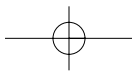
Sui-ping wrote down Ya-pin's home address.

For more than three years since then, sisters of the Order in their seventies would get on a bus taking their lunch boxes with them, paying visits to Ya-pin every Friday. They would talk and sing gospels to ease her suffering and provide a vent for that bad temper of hers. With their kindness, the sisters were able to help steer Ya-pin away from constantly complaining to God that life was not fair. Slowly but gradually, they began to lift her spirits.

One of the Franciscan sisters said, "Everyone bears a different cross. Perhaps you are carrying this cross for others."

Ya-pin still can recall each and every word. These words brought her back to life, sparking a flame within her heart and helping her become someone for Sui-ping to lean on in times of need. Whenever Sui-ping was emotionally troubled and could not find a way out, Ya-pin used these words, thereby transferring their power to her big sister.

What the Franciscan sister had said about carrying the cross was unexpectedly linked to genetics. The cross of genetic disorders was not being carried for any sins that had been committed. There is an inherent risk that during the course of evolution over several generations, genes which cause genetic disorders could appear in any family line—it is merely a question of probability. Those who inherit



such a gene are carrying the cross for all our sakes.

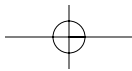
Constructing a Citadel for the Mind

If one travels far enough, one will always find a beautiful garden. The social welfare system in Taiwan has improved considerably over the past few years. When Ming-hua was in hospital, Taiwan's National Health Insurance system went into effect. Her nursing care costs, however, were still extremely high...was there any hope of obtaining some coverage? Sui-ping had never received any form of help, despite having asked for it from the Department of Social Affairs. But this time, a volunteer worker at the information desk in the hospital enthusiastically informed her of the Physically and Mentally Disabled Citizens Protection Act, according to which Sui-ping could apply for benefits. Depending on the severity of the illness, one could receive three to six thousand New Taiwan dollars a month.

Her younger sister and brother Ming-hua and Ke-ying later moved to a nursing home on the outskirts of Taipei, greatly alleviating their big sister's financial burden. This was especially helped by the fact that the now divorced Ke-ying was eligible for low-income welfare benefits, and began receiving NT\$15,000 per month. Sui-ping could finally breathe easily as all her siblings now resided in Taiwan.

Surprisingly, Ke-qin left for Mainland China.

It started in 1995 when he began to have trouble buttoning his clothes and tying his shoes. He spilled his soup and had to support himself on a wall while walking. Once athletic, he had lost his strength. This caused the whole family to fall into depression and be drawn to his cries of woe.



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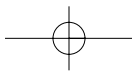
Ke-qin remembered when he was twelve, carrying his mother down the hill from their Keelung home to get a shot for her from the doctor. When older, he had to carry his big brother Sui-yong to get acupuncture. Death's eyes had been constantly peering out of the darkness. He saw a reflection of his future self in his family. He was first heartbroken, then frightened, finally indifferent. He said that the burning fire in his heart had been extinguished.

Before he got sick, Sui-ping often reproached him for not utilizing his strong body to help with the family burden. After a long while, he answered, "You didn't understand me. I've been always living in fear."

Having seen the endless suffering of his siblings, he wanted to do anything he could to help in the beginning. But this disease was utterly ruthless and unrelenting. After the condition of his brothers and sisters deteriorated, he could no longer recognize them as they used to be. Seeing this horrific prelude to his future made him anxiously hold on to whatever time he had left. "My life is decades shorter than others. I have to work harder than they do while I'm still strong."

He crawled out of depression and earnestly searched for Chinese medicine treatments combined with Western medicine in the mainland. His wife loved him very much, and their child felt the love deeply. Even at the young age of six, Ke-qin's son was precocious to the point that endeared him to everyone. He was already able to fetch water for his father and help him walk. He will tell you now "Who knows if I am spared by heredity."

As long as the family did not give in, the mind could not be broken. The future was not black. His younger sister Yan-fen was an example for him.



Walking became a fear of Ke-qin's after he fell once. After getting sick, small fears manifest themselves in every part of life. As these fears build up, the citadel of the mind begins to collapse piece by piece. Ke-qin realized this, and using the strong will of an athlete, he meditated, practiced Qi-gong, and practiced walking. Late at night in a virtually empty park, he practiced walking until it became a mechanical reflex and his body had memorized the movements. The cane he used up until 1999 was cast away the following year.

“We cannot choose who our parents are, but we possess the opportunity to change and create our own destiny.” He forever holds on to hope, serving as an example for generations to come, in case they suffer a similar fate.

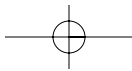
Reunited in a Nursing Home

Ke-qin stayed in Wuhan on the mainland to fight alone, while Sui-ping took trips back and forth from Taichung and Taipei to visit her brothers and sisters.

A regular gathering of the siblings was held in the nursing home.

Sui-ping placed a pillow behind Ming-hua's back and gently helped her sit up straight. She brushed her hair. Ke-ying was staying in the room next door, and was pushed to his sister's bedside in a wheelchair. He could not speak properly, so he just watched them in silence. Ya-pin rolled over to the bed in her wheelchair, using one weak hand to hold Ming-hua's even weaker one, while using the other to cover up her own sobs. Ming-hua was too weak to lift up her hand and wipe the tears away, so they flowed unchecked. Yan-fen stood beside them, whose eyes and nose were already red.

In the midst of this room filled with sniffing sounds, the brothers and sisters greeted one another.



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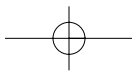
In spite of Ming-hua's stiff body and lethargic tongue, her mind was crystal clear. The pain in her back was excruciating, so all she could do was to stay quiet and bite down. Her teeth came together in such a way that her lip started to bleed. Sui-ping wiped it with a cotton swab and cleaned the blood from her teeth. Using the native language of their mother from Yunnan province, Sui-ping said, "Try to move your arms and legs a bit more...you have such great computer skills. In the future you won't need to use a hand-controlled mouse; soon they'll be eye-controlled. Be patient, don't give up on yourself."

Sui-ping cared very much for Ming-hua, her keen-witted, intelligent little sister. Ming-hua had planned to use documents signed by a neurologist to apply for early retirement benefits, however later she was re-diagnosed as having a disorder treatable with physical therapy, whereby she did not qualify for a reasonable retirement package. Costs kept piling up for the next few years, all the while losing the warmth she once received from her husband. Sui-ping once thought of persuading Ming-hua to divorce her husband so that she would be eligible for single head of household, low-income benefits like Ke-ying was. But Sui-ping reconsidered, and decided it was best not to. Ming-hua would be unable to cope with even greater isolation by divorcing her husband.

Ming-hua's case is a typical example of what happens to handicapped persons and their families. Some husbands and wives divorce in order to receive more welfare even though they still live together. Nevertheless, this kind of arrangement could bring unexpected changes to a marriage.

A Home Needs Warmth

What Sui-ping hopes for the most is specialized care for families



afflicted with similar genetic disorders. She wants to rent a place close to her home, where a Filipino helper could be hired to partake in the care of her siblings. Ke-ying, however, is required to live in a legal nursing home to qualify for medical benefits. “Why are there such restrictions? We are willing to be inspected by the government,” Sui-ping said in frustration.

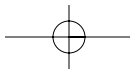
The only place suitable for living is in a house of warmth. Only then can it truly be called “home.”

Further away from Ming-hua's bed, Ya-pin and her brother started chatting. Laughing silently, Ya-pin said, “Do you remember the time we went biking in Nan-ao on the east coast? You called me stupid, but you were even dumber. You couldn't even get on the bike, ha-ha.” Although they had already started to show symptoms then, they still managed to have several happy moments by the sea.

Speaking of the past lifted the dead air in the room. Wiping her eyes, Sui-ping remembered fun things their family had done together: “When Yan-fen was in college and didn't know she had been adopted, Mrs. Xia was afraid she'd be too lonely and encouraged Yan-fen to know us better, but was afraid we wouldn't accept her! She always took Yan-fen to our places, and when Ke-qin was dating, he took his girlfriend out with Yan-fen. After she got home, she said to Mrs. Xia, 'That idiot was taking me to see a movie!' Then Mrs. Xia said, 'I don't trust you going with anyone to see a movie except him.'”

The room filled with laughter, and Yan-fen's loving husband brought some cold drinks. Everyone drank some fruit juice that afternoon, and in each other's company felt the warmth of family.

“If you're rolling around in your wheelchair and fall backwards it's because you're using too much force,” Ya-pin coached her little



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brother. “When you sit down in it you can't lean back. Steady yourself first. You can try and see for yourself.” Her brother happily listened to his sister. How lonely was he most of the time?

All Sui-ping hoped to do was love and care for her family. Obstructing this dream, however, were government regulations.

Ming-hua greatly depended on her big sister. From Ming-hua's blinking eyes Sui-ping knew she wanted to tell her something. Sui-ping wrote out the phonetic pronunciation symbols for Chinese used in Taiwan, pointing to each of them until Ming-hua blinked a “yes.” Sui-ping read out loud, “‘Stronger sleep aid’? OK. But no more asking me for a knife.”

The corners of Sui-ping's eyes reddened as she spoke. Sleeping well and painkillers were a big deal now. She knew Ming-hua lived in pain, and it sometimes took hours before Sui-ping understood anything her sister was trying to tell her. Although it was hard, she could not let Ming-hua make attempts to take her own life. As long as one lives, there are an infinite number of things to look forward to.

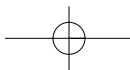
Hope

Sui-ping looked at herself. It had taken a few years to learn how to stand back a bit and confront life's hardships with a cool head.

Six years earlier, a drawing class was opened for employees at the Postal Administration. Her life-long dream of delving into the realm of painting had finally come true. In the deep strokes of her brush, she tried to immerse herself within painting as a form of meditation.

“Painting is a kind of therapy for me.”

One of her paintings is called “Hope.” It is the clearest reflec-



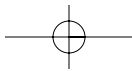
tion of the paths her mind has gone through. In front of farmhouse, a hen leads her six or seven chicks walking in front of a closed fence, hoping that it would eventually open. Sui-ping's brush worked delicately, rich in meaning. This is an image of what has accumulated in her mind over decades. Once stirred, inspiration poured forth. This oil painting was completed in just three days, and while working with the brush, she was also pouring out love for her siblings.

She had always been reluctant and unwilling to speak of the torment brought on by her family's illness, keeping everything bottled up inside and reading all sorts of materials in the search for answers to the several riddles in life.

Then she unexpectedly came across the book *A Care-Giver's Guide: Practical Solutions for Coping With Aging Parents or A Chronically Ill Partner, or Relative*, by Jill Watt.² In this book the author discusses how the care-giver must adjust their mentality to maintain a sense of oneself and to plan ahead. In this way the care-giver will be able to provide adequate care to others while preserving their own quality of life.

Reading this book caused tears to flow down Sui-ping's cheeks as she realized the existence of this blind spot she had all these years. By caring for her family with all heart and no sight, her sense of self had been lost. She was unhappy because she did not love herself, and her unhappiness was transmitted to her brothers and sisters, sparking a vicious cycle.

"One must harness the power of many to understand life," Sui-ping sighed. These words provided Yan-fen with the determination to establish a Spinocerebellar Ataxia Association, and Sui-ping gave all the support and help she could. In addition to caring for her brothers and sisters, Sui-ping ran several errands, becoming a



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spokesperson for all who were unable to speak out.

“Why don't you join us,” she said gently while brushing Ming-hua's hair. “Yan-fen is counting how many patients there are. After the association is set up, everyone can help each other”

Ending the Catastrophe this Generation

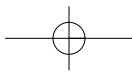
On the day the Association was established, both Spinocerebellar Ataxia and Huntington's Disease families walked hand-in-hand.

The lights flashed one after another on the pale, slightly deformed face of Ming-hua which had once been so beautiful. On that day, June 18, 2000, she agreed to attend a press conference with Sui-ping, and rode in an ambulance lying on stretcher while breathing through nasal tubes. This helped receive much press coverage, using Ming-hua's dismal appearance to attract the attention of society. Seeing the hardships spread throughout a family and across generations with your own eyes, makes you see that the sick do have the inalienable right to survive and live with dignity.

On stage, Ming-hua's sisters were accompanied by other patients and their family members, and began singing in chorus while holding aloft small candles. The song was a gospel they had worked on very hard for several weekends. When one's energy is almost spent, the hymn sparks an inner light within the person listening:

*Unlit candles; how can they give light?
Unlit candles; how can they give warmth?
But if lit by the flame,
They are like real sunlight in the cold of winter.*

Nothing is said; how can one hear?



*No love is shown; how can one feel?
But when the words flow forth uninhibited,
They are the most beautiful words in this world.*

The candlelight emitted the gentlest of cries, the swelling tears flowing yet unable to wash away the pain of illness. Families faced the media, not to receive sympathy, but in the hope of enjoying equal health-care rights, struggling for their illnesses to be classified as severe for larger benefits, and calling for the establishment of a nursing home for mentally sound patients with severe physical impairment.

Their sobbing voices slowly overcame despair and moved them towards hope:

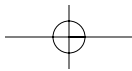
*The light needs to shine forth, love must be shown.
From this one can see, true love is in your midst.
The light needs to shine forth, love must be shown.
From this one can see, true love is in our midst.*

Survival is an instinct inherent to us all. All are entitled to enjoy the benefits of social security. Everyone has hardship in their lives. Social security exists to amass collective resources of the many, and assist those who face danger alone. Does not creating a responsible, humane society mean providing help to society's darkest corners?

Ming-hua was speechless with watery eyes, but still emitted the most painful cry for help.

Three months later, this pair of eyes succumbed to fatigue and closed forever.

How many more generations must undergo this suffering and



pass on such genes, all the time unaware who might inherit them in future generations?

According to estimates from Dr. Soong Bing-wen, Director of Neurology at Taipei Veterans General Hospital, about eight to ten thousand people in Taiwan have Spinocerebellar Ataxia. At present, the Spinocerebellar Ataxia Association is carefully working on a plan to promote prenatal screening for the gene. Yan-fen is the director, and her husband is responsible for the pamphlets. They sincerely hope that member patients can work together in promoting preventive genetic screening of embryos, and stop the hardship from being passed on to the next generation.

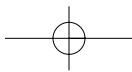
Day by Day

I still remember when Yan-fen poured me a cup of tea that spring day, talking about the lives of her family members. A few months later, she wanted to go skiing with her husband in Europe. One would get some pictures for advertisements and the other just tag along. “Just the two of us, I already got my wheelchair packed to go, woo hoo! He's going to carry it for me...,” Yan-fen said.

She couldn't help but laugh when we started talking about “Chauffer Li,” because her dear and loving husband would take his wife to the doctor, attend Buddhist classes or see her sisters whenever he could. The refined and cultivated Chauffer Li didn't say much, but he never failed in providing words of support to Yan-fen. “Take better care of yourself so we can go have some fun!” he'd always cajole at his wife.

This family uses love and joy as medicine, forming a light and clean air which spreads throughout the room.

Yan-fen's foster mother Mrs. Xia was in the kitchen busying



about, and said, “Yan-fen is lucky. When her father was alive, he never let her wash a single dish. She was always playing outside all day and never learned how to do any chores.” In the living room, Yan-fen was leaning at the doorway eavesdropping in on her nagging, all the time covering up a great big laugh.

A devout Catholic, Mrs. Xia had a positive outlook on life. In a soft voice she said, “I’m better off that my daughter’s condition keeps me busy. The Lord wants me to do good deeds so that my life won’t be wasted.” Yan-fen turned away from her living room eavesdropping spot when she heard this, the twilight falling upon her thin shoulders.

Yan-fen said that if her condition became serious, the person she would worry about most would be her foster mother.

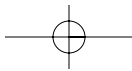
Children slowly but surely grow up. Yan-fen never hid the fact from her children that she has a dominant genetic disorder so that they can face it from a young age. If and when they become sick, her daughter and son can support one another. They have already begun to learn by helping their mother walk. Yan-fen will take them to test for the gene when they are a bit older, and the doctor will be instructed to tell them the results when they become adults. Despite their having to wait, she still decided to tell her children about the family illness much earlier.

“It’s cruel,” she sighed. “But I think the more time there is, the easier it will be to accept the reality of it all in the future.”

Are the children worried they might have the gene?

“Very worried,” blurted out Yan-fen’s eleven-year-old daughter. “I don’t want to be sick like mom.”

So direct and quick an answer showed how worried she was. A while later, she laughed and said, “But when we’re happy there’s



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nothing to worry about, and we're happy most of the time!”

There was so much pain in Yan-fen's eyes.

She had been determined from a very early stage to hold on until her children could care for themselves. The only available treatment was experimental, so Yan-fen stopped resorting to it long ago. But she has never given up her religion as a spiritual form of treatment, and has aspired to reach the limits of her soul with greater devoutness. She uses her mind to carry her body, not her body to carry her mind. As for how long this illness will continue, she doesn't want to think about it, and lives on day by day.

It is the sanctuary of religion that frees us from bodily suffering, connecting our minds with all living creatures. Yan-fen has a great wish—she hopes she'll be able to raise enough money to build a community that serves as a nursing home to provide the necessary care for patients unable to care for themselves. They would not need to be separated from their families, and there would also be full-time care-givers to lift some of the load. There would be a small emergency room, a therapy room, and best of all, a movie theater...

Yan-fen's eyes glowed with hope.

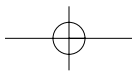
Was she really slow in reacting? Yan-fen had opened a wonderful window of hope.

God's Riddle

God's riddle was so difficult to unravel...

During late autumn in 2000, Yan-fen did not go skiing—she went to Veteran's Hospital instead.

Her thin shoulders had become thinner and her voice weaker than before. She rested and appointed her brother Ke-qin, who had returned from mainland, as acting director for the Spinocerebellar



Ataxia Association. However, this time it wasn't Yan-fen who was admitted to the hospital. Yan-fen unsteadily walked towards the sickbed of her husband. It had been one week since her husband had a stroke and was partially paralyzed. Now in the hospital, he was holding the TV remote looking around, recognizing neither what device he was holding nor the family and friends in the room.

The children, who were only in elementary school, complained they were hungry. Standing up from the corner seat she had once been sitting quietly in, Mrs. Xia took them outside to find something to eat. With her sound mind and body, Mrs. Xia as able to calm this upset family as she had always done.

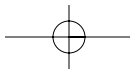
Yan-fen lightly patted Chauffer Li's hand and quietly looked at the visitors and their surrounds, her gaze finally sinking into the hospital's white walls.

“This is my fate,” she quietly said.

She neither sighed, nor said anything out of anger to heaven, nor challenged its will. It seemed she thought that hidden within the bitter taste of life, something sweet might come of it as long as one chewed long enough.

Chauffer Li sat up in bed, always appearing to be meditating slightly nodding his head.

Yan-fen sat at his side. As I placed my arm around her thin shoulders, I hoped that she knew everyone felt for her and was willing to be with her in this time of need. She was not alone as she cried. I wondered..., was I comforting her? Or was I comforting myself in facing the fact that life could be so brittle? Perhaps how Yan-fen's beautiful white face was not carrying any worrisome expression—as it always did—proved how accepting she was compared to anyone else present, despite the fact that life treated her



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most cruelly.

What is it that empowers one to endure suffering and illness?

If life is about deeply exploring the soul, then what is our mission?

I want so much to see things as Yan-fen does, that world where everything is filled with the mysterious energy of the soul...

Struggle with a Wavering Body

During Chinese New Year in 2001, the sisters had a reunion in Taipei and were discussing where they should go to eat.

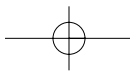
“Does anyone want to eat Chinese pastries?” Sui-ping asked.

Someone's left hand rose, but no one spoke. Everyone looked and laughed with great joy, for it was Chauffer Li's hand. Although he still had not fully regained his powers of speech, he had regained his mind. After three months of physical therapy in Cheng Hsin Rehabilitation Medical Center, he was able to slowly make his way up and down the stairs.

“He's still young and recovering quickly. Although there's some trouble with his right side, he's made a lot of progress,” Yan-fen said in her sweet, calm voice. In addition to visiting her husband in Rehabilitation Center, she was also going to a Chinese medicine clinic in Sanchong, Taipei County, to try out new treatments for herself. “People can overcome any obstacles thrown at them!” she said with enthusiasm.

The reunited family had a joyous Chinese New Year as always.

With all the hard work Sui-ping had been doing throughout Taiwan, this garden in a hopeless land finally started blooming in spring. Taiwan SCA Association was recognized by the government in March 2001. Dr. Soong's so-called “the group that struggles with



wavering bodies” not only became a family with soul, it now had more resources with which to promote a system of care for their family and others like them. The office, which had troubled Sui-ping for sometime, was provided by patients' family members. The first thing the association did was modify a nine-seat minibus, making it possible for volunteers to drive patients to and from the hospital.

The sisters said their big sister Sui-ping was one of the greatest people they knew.

Sui-ping forced a smile, saying “I don't want to be great. The price for being great is too high.”

Being healthy, after all, is the most joyous thing in the world of mortals.

The body might waver, but not the conviction in the search for dignity and respect. Can what heaven forgot to bestow them be supplemented with the sympathy and love of others?

Notes:

1. Pollin, Irene, with Susan K. Golant.

Taking Charge: Overcoming the Challenges of Long-Term Illness.

Times Books, 1994

2. Watt, Jill.

A Care-Giver's Guide: Practical Solutions for Coping With Aging Parents or A Chronically Ill Partner, or Relative.

Self Counsel Press, 1994