FAREWELL, MY MOTHER: A DAUGHTER'S MEMOIR OF DEATH WITH DIGNITY

斷食善終：送母遠行，學習面對死亡的生命課題

Facing an inherited degenerative disorder, the author's mother chose death with dignity over a life of suffering and extreme disability. This book records this wise and courageous journey, and its impact on the author's family, confronting vital questions of what it means to live and die well.

Despite knowing her mother's family history of spinocerebellar ataxia, or SCA, physician Bih Liu-Ing is shocked when her mother begins displaying the telltale symptoms of impaired movements and wobbly gait. A neurodegenerative disorder that causes atrophy of the cerebellum, SCA usually shows by middle-age, so the family had always assumed the fatal gene had bypassed Dr. Bih's mother. Confirmation of the diagnosis sends shockwaves through the family, laying bare old family wounds, and forcing them all to engage in difficult conversations, ultimately leading to the mother's decision to choose death with dignity.

Earlier in her career, Dr. Bih had read Japanese physician Nakamura Jinichi's book on the fasting method of assisted suicide in which the patient reduces their food and water intake until the body can no longer sustain life. As death approaches, the body produces natural endorphins that induce a state of calm. Dehydration eventually leads to unconsciousness, allowing the patient to die a natural and relatively painless death. When the time comes, Dr. Bih introduces the method to her mother, giving her the option to choose the humane death that she desires.

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The book opens with the family's history of SCA, detailing the suffering endured by the author's uncle and cousins as they gradually succumbed to the disease. The following chapters develop a psychological portrait of the author's mother, addressing the impacts of growing up in a time when women weren't valued beyond their role in the home, her cold and distant father, and a marriage that afforded her little dignity. This complete picture of the mother's life helps to contextualize the loss of personal value she experiences as the disease progresses, and her decision to exit life on her own terms.

The middle chapters detail the mother's direct experience of the illness, both physically and psychologically. During the early years she slows its progress with rehabilitative exercises, but eventually loses the ability to live independently and care for herself. In parallel, Dr. Bih records her mother's process of coming to grips with her life and her mortality, releasing her past grievances and traumas so that she and the entire family can prepare for her passing. Details of the fasting process, the emotional responses of each family member, and even the pre-death farewell ceremony are included.

In the final chapters, Dr. Bih follows up with a discussion of end-of-life care in Taiwan, including legislative issues, and comparisons to other countries. The final chapter of the book records the reflections of the entire family once the process is complete, as well as collection of moving reactions from online readers.

Both as a physician and a daughter, Dr. Bih Liu-Ing reflects on her mother's wisdom and courage in the face of death. This faithful record of carrying out a loved one's wishes concerning death, and supporting them in their final moments, is enhanced by Dr. Bih's knowledgeable discussion of the moral and medical issues associated with end-of-life care. Written expressly to prompt readers to contemplate these difficult topics, *Farewell My Mother* is sure to encourage discussions about what it means to live and die well, while also providing comfort, healing, and practical advice to those already struggling with terminal illnesses in their own families.

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By Bih Liu-Ing
Translated by Brian Skerratt

Chapter 1: The Genetic Screening

It was 2001. I was planning my visit home to see my mother during Chinese New Year when she told me over the phone that she had been walking less and less steadily. Now she even needed to hold the railing going up and down stairs. Actually, she had been complaining about unsteadiness and occasional falls for years already, but the truth was, in addition to taking care of my father since his stroke, she had been handling all manner of exercise and housekeeping with no problem at all. I thought for sure she was worrying for no reason.

So I was surprised to find, when I saw her a few weeks later, that she was noticeably thinner, and that even standing with her feet together made her wobble badly. Forget about standing on one foot. I'm sure my dismay registered on my face. Mother started asking me, "I've got it, haven't I? I've hit the jackpot? But I'm already so old – why would it start now?" Her questions produced nothing but blankness in my mind. I couldn't find the words to respond.

Twenty years earlier, my cousin, who was only three years younger than my mother, came with his teetering gait to the neurology department at National Taiwan University Medical School, where I was a resident. After a series of tests, the department head gave him a rare diagnosis: spinocerebellar ataxia, SCA. He asked me to investigate my family history carefully and to give him whatever information I found. It was only after I started asking that I discovered that from age thirty, my mother's brother had walked like a drunk, and that it was due to this very same disease. Three years before, his son was also diagnosed with SCA, that uncle had surgery to relieve pressure on his spinal cord, leaving him unable to urinate without assistance, and his legs nearly paralyzed. He never walked again. My mother's mother was perfectly healthy before she died giving birth at age forty, but many of her relatives had walked unsteadily before old age and were eventually confined to bed for long periods of time. From the bits of information I gathered, it seemed that men and women suffered from the disease with equal probability, and that it was a dominant genetic trait: as long as one parent had the disease, each child had a fifty percent chance of inheriting it.

That was when fate turned cruel for my uncle and his family. After five years confined to his bed, my uncle tied some electric wires around his neck and rolled out of bed, strangling himself

to death. Ten years after his own diagnosis, my uncle's son suffocated himself with a plastic bag and died struggling for air. His younger brother developed symptoms in his twenties and spent seven or eight years unable to walk, speak, or swallow; he died with his joints distorted, covered in sores, and so emaciated he looked like a sack of bones. He was only forty-two. Several of their own children started showing symptoms as early as their teens or twenties. The disease has a peculiarity, called anticipation, where each successive generation shows symptoms earlier than the last. My cousin's wife, seeing her daughter, two sons, and husband all come down with this condition, took to drinking, developed depression, and finally died a few years later of unknown causes.

Ever since, our family has lived with the shadow of hereditary illness darkening our minds. My mother's elder sisters were not showing any symptoms, and she herself was already sixty-four, well past the typical age for the disease to strike, which is thirty to forty. As a result, the topic rarely came up. Even I, as a medical professional, had never considered facing the problem directly, even after I learned that genetic testing was available. Instead I chose to bury my head in the sand, believing that my grandmother had passed on the genes to her sons only, and my female family members had been spared.

Now that I had seen my mother's obvious loss of balance, I knew things looked bad. My mind was running a mile a minute, but I played it cool, reassuring my mother, "Go see the doctor first." My husband was disturbed when he heard the news, as if he'd been suddenly wakened from a dream. He lay awake at night with worry, and then felt the need to console me, for fear that I couldn't bear the shock of this development. I could almost see his hair turning white before my eyes.

I went with my mother to the neurologist, where the doctor performed physical tests. Mother's balance had noticeably deteriorated, so he sent us for lab work. I could sense what was coming, that our fate was sealed. Still, we had to wait for the genetic testing results to come back, and an MRI was scheduled to help with the diagnosis. Mother said the half an hour she spent in the MRI seemed endless. Her whole body quaked beneath the thin robe and scanty blanket. Trapped in that enclosed space, she could only think, what would happen if the machine malfunctioned? The machine would emit different noises from time to time. When would it start making noises again, she wondered? What kind of noise would it make this time? To her, it was a terrifying, interminable test of her nerves. I realized that we in the medical profession often forget how challenging even routine procedures can seem to our patients.

Mother had an inkling of what was in store. Still, she asked me repeatedly if it could be any other condition. I told her it was possible it could be something else, like an infection or a tumor, which was why she had to get the MRI. She said she hoped it was anything else, anything other than spinocerebellar ataxia. She'd rather have a brain tumor – it could be cancer for all she cared – she'd happily have brain surgery and die in the process – as long as it meant she hadn't passed SCA on to her children and grandchildren. My heart went cold.

I brought the MRI images to my friend, the head of radiology. I asked, "How old would you say this patient is?" "About fifty. I only see a small dark spot. The rest is normal." I said the patient

had a family history of SCA and had already demonstrated loss of balance. He said, “Now that you mention it, the image is consistent with SCA.” In the early stages of the disease, the atrophy of the cerebellum is still mild; her brain’s overall condition was still within normal limits. I talked it over with my husband. We agreed to keep this a secret from the entire family, to prevent my younger brother and sister from having to endure the excruciating knowledge of Mother’s condition.

My husband, an obstetrician, could make use of prenatal screenings to prevent our sons, nieces, and nephews from passing on the gene to their children. We couldn’t bear the thought of a third generation – still so young – carrying this burden. I told my mother over the phone that she didn’t have SCA, only some past strokes that had gone undetected, and that her loss of balance was due to aging, nothing more. She couldn’t see the unnatural expression my face took on when I was lying (with me living far away in Taichung), but she still knew when her daughter wasn’t being truthful. She insisted on going for genetic testing anyway.

When Mother received her report at Taipei Veteran’s Hospital, the result was type three spinocerebellar ataxia, the most common type in Taiwan. The genetic counselor was shocked that she had come to get her results alone and remained so unusually calm in the process, without betraying any signs of terror or grief, and praised her strength repeatedly. Mother was already taking computer classes at the time, and now she told me she wondered if she should take English classes too, in case she had a foreign caretaker one day. She wanted the three of us – my brother, my sister, and me – to get tested. She was old, she said, so it didn’t matter that she had the disease. What she couldn’t stop worrying about was her three children and three grandchildren – what if they had it? Even worse would be her grandchildren someday passing it on to a further generation.

I was opposed to anyone without symptoms getting tested. With no effective treatment, knowing early was no help; it could only affect us psychologically. Especially the kids – how could they live with that knowledge from such a young age? Mother felt they absolutely should know if they carried the gene and should tell any future partners. They couldn’t repeat the mistake of my cousin, who kept his wife in the dark; after he and the children all left her, she never forgave him. (Their daughter had started showing symptoms at age ten and passed away in her twenties.)

I said if the children found out they had it, would they ever even have the chance to have a partner? They could never hide the truth, and if any romantic interest found out, they’d certainly be scared off. The only way they could ever have hope of dating normally was not to know.

“That’s not fair to the others!” my mother objected.

“Aren’t you the one who always told us life isn’t fair?” I said. “It’s only because there’s early testing that we even have this choice. Who can guarantee they won’t ever have a stroke, or get cancer, or have an accident?”

From my uncle and his sons, my mother had seen the gradual deterioration brought on by SCA. She had seen my cousin, emaciated, covered in bedsores, arms and legs deformed, feeding tube stuck in his nose, with no way to talk. It was she who brought up the question of euthanasia in case she reached a similar point. We had reached consensus on the matter long ago – if anyone contracted an illness serious enough that continued living would only bring suffering, then we would not force resuscitation and prolong that agony. I knew that Taiwan would not legalize

euthanasia anytime soon, but she reminded me: she needed me to help her escape! I was the only doctor among her three children, and so she rested this hope on my shoulders. I asked her at what point the illness would make it unbearable for her to go on living. She said, "When I'm in a wheelchair, unable to take care of my family, and instead need someone to come take of me!" That's quite harsh, I thought to myself – by that standard, a lot of people had no right to go on living. Our rehabilitation department was full of patients in wheelchairs, who would never walk again! I consoled her, saying that the disease moved more slowly the later in life it appeared. She would be just like other old people, gradually finding life a little more difficult. She didn't need to worry so much! But I was only trying to make her feel better. She well knew what lay ahead, from the experiences of my uncle and cousins. Walking would become less and less steady. She would lose coordination in her hands. Swallowing would become difficult, her speech would grow slurred, and finally she wouldn't even be able to sit up, but only lie in bed, fed through a tube. I couldn't let her get to that point!

I relayed our conversation to my husband, saying that if this disease left me severely paralyzed, I also hoped to be put out of my misery. I didn't want to live in pain, without dignity. I also told him, if I died first, I wanted him to remarry. He quickly responded, "Don't you dare do anything rash. If you're making any decisions, you have to tell me first. I will always stick by you and take care of you. If you're not here with me, then I just want to live my life alone in peace. I don't need anything more than that."

In my many years as a doctor of physical medicine and rehabilitation, I've treated countless patients with severe disabilities. In the beginning, it's common for them to attempt suicide, or lock themselves at home and refuse to come out. And yet, a majority of my patients with spinal cord injuries were able to overcome their mental and physical barriers and return to work, to rejoin society, and I was filled with admiration for them. As I thought more about it, how could I be so weak? "Don't worry too much," I told my husband. "I've been thinking. Each time I see something beautiful, when I listen to music or read a book, I still feel the beauty of life. As long as I can still see, still hear, still read – then life is worth living!"

Our elder son, who had recently been accepted to medical school, mentioned that he'd been bumping into doors recently – I'd read that one early sign of SCA is bumping into people or walls. That night I lay awake thinking, if he has SCA, what medical specialty could he practice? Meanwhile, our younger son, still in middle school, started growing suspicious about why his parents seemed to halt their conversation each time he walked into the room. Even stranger, they'd been asking him and his brother to do all sorts of strange movements – balance tests, unbeknownst to him. Mommy had been doing those strange movements for daddy, too.

The only thing that had changed since Mother's diagnosis was our mental state. Suddenly the simple pleasures we had known seemed out of reach. I started to fall out of touch with old friends – how could I tell them these things, explain this stress? And if I didn't mention it, how could I feign serenity, face them with a mask? After a bout of crying, it struck to me that the torment of not knowing was exactly the same as if I'd already been diagnosed. I decided I may as

well get tested – there was a fifty percent chance we could all be relieved of this pain. If it turned out I had inherited the disease, then my situation wouldn't be any different than it was now.

Mother called me to say that the fortune teller told her she was just getting older, that she wasn't going to die from any congenital illness. She was hoping to comfort me, make me stop worrying so much, because, in fact, the fortune teller had told her, "Your elder daughter is taking this harder than you are!" I informed her that I'd already had blood taken for the genetic test, and I'd be getting my results soon.

I didn't want the matter to come to light at my workplace, so I had my husband take the blood sample at his private practice. The weeks I spent waiting for the result were nearly unbearable. The moment my husband called me at the hospital to tell me the result was negative, I felt so happy, I wanted to tell the good news to every person I saw. Thank heaven and earth, it was negative! I hurried to call my mother. She said that of the six stones weighing down her heart, she could now put down three of them – one each for me and my two sons. But there were still three stones she couldn't put down.

Later my husband told me, if the test had been positive, he still would have told me it was negative. Alarmed, I demanded to know, was I negative or positive? "Negative, of course!" But if I had been positive, he said, he would have tested our sons secretly and not told them the results.

That is what we did, in fact, for my nephew. We didn't plan to tell my brother or sister about any of this, in the hopes that they could continue to live in the blissful ignorance we now longed for. We only wanted to find out if my nephew had the gene. Of course we hoped he didn't, but if he did, would still wouldn't tell him; we would just make sure to screen his spouse secretly early on in any pregnancy. So when my nephew came to Taichung for a few days, my husband took the opportunity to take his blood, claiming he would send it for biochemical tests, when in fact he was looking for the SCA gene. Again, I must thank the god of heaven: my nephew's test was negative. That meant my niece also had a very high chance of being negative.

I felt that, since the third generation had escaped disaster, there was no need for my brother or sister, already middle-aged, to undergo testing. My mother still wished they would, though. I thought this must be a mother's unique burden: she needed to know that all her descendants were free from the disease before she could let go of her guilty conscience. I shared these thoughts with her, saying I hoped she could let it go. None of us blamed her, just the way she didn't blame my grandmother. After that, she stopped insisting that we tell my siblings.

A few months later, my mother told me my sister had actually been haunted by the possibility of genetic disease for years. She happened to see a news report about SCA, and suggested that my mother go get tested. Since she brought it up, we decided to let her in on the secret. I thought if she knew that her only child was negative, she would relax. Little did I know that she would insist on getting tested herself – and since I knew my own state of mind before getting my test results, I couldn't very well dissuade her. Luckily, she was also negative. Both my mother and sister heaved huge sighs of relief.

My brother, the last to know, was only concerned about his dear mother; he had no thought for himself. Mother couldn't convince him to get tested. He said he was very busy with

pressing work, so how could he have time to worry about the future? He had no children of his own, so we urged mother to let the matter drop. It was good that he could put it out of his mind. Why should he have to look into the future and open such a can of worms? All we can really control in life is the present. Why frighten ourselves thinking about what might happen? I could see it from my brother's point of view now, but when I was the one facing the unknown, there is no way I could have been so blasé.

So despite the terrifying rollercoaster ride, in the end there was nothing to fear. Still, my husband and I had changed fundamentally in our attitude towards life. We became aware of the insignificance of human life and its lack of predictable constants. Life was truly to be cherished, lived to the fullest! In spite of our newfound appreciation for life, neither of us could imagine how we would feel if the tests had been positive. During the entire process of genetic screening, our positions as a doctors gave us access to resources that ordinary patients would not have had, which we used to take care of our family members as we thought best. As a healthcare provider, I have unwavering faith in genetic counseling, and yet, after going through this experience as a patient, my point of view had changed completely. According to current rules, minors cannot be evaluated for the condition, while for adults, only the tested individual may see the results. Fetal testing is allowed, and when necessarily abortions are performed according to the Genetic Health Act. In some developed countries, abortion is not allowed for SCA, since it affects individuals only in middle age.

While I was waiting for the results of my test, I received a call from a Miss Chu Sui-ping. She told me that she and others with SCA, along with their family members, were forming the Taiwan Spinocerebellar Ataxia Foundation, and invited me to serve as an advisor. It was only after she explained how she found me that I remembered the column I'd published on the disease ten years before. At that time, Miss Chu had called me after reading the article, saying, "My family has a similar story to yours. Is there any treatment for the condition?"

"There's no drug that specifically treats SCA," I said, "but rehabilitation can delay the worsening of symptoms." She mentioned that her mother had committed suicide after spending years paralyzed in bed. After a few years, her six younger brothers and sisters had all started showing symptoms; she had taken care of two of them personally, which was an extremely difficult task. I told her how a foundation for patients of spinal cord injuries and their families had provided immense support to my rehabilitation patients. At the time, I didn't anticipate that she would make it her mission to establish a foundation for SCA, and that after ten years, her vision would come true. I felt full of admiration for Miss Chu, not to mention surprise that our phone call ten years earlier had led to such a development. My own family members would go on to receive support from her organization.

In March 2001, the foundation held its first meeting in Taipei. The director was a cousin of mine who did not have SCA; another cousin's son and daughter were there as members. I felt a pang as yet another cousin's daughter, only thirteen years old, arrived with an unsteady gait, leaning on her mother. For my part, I attended as an advising physician, so a lot of people didn't realize I was also a family member affected by SCA. In my speech, I emphasized that SCA is not a

death sentence: it just means that the cerebellum ages faster than normal, but rehabilitation can slow the deterioration, the same way that exercise and a healthy lifestyle can slow the aging process.

Over the years, I've cared for many SCA patients at my hospital. Rehabilitation is useful for patients who aren't getting enough exercise, as long as they keep it up at home. Still, as their condition inevitably worsens, patients may need to come back again, to learn new ways of exercising and adjust to new mobility aids, such as canes or wheelchairs. The physical therapists at our hospital frequently speak at the foundation, and they were the ones who put together the foundation's health instruction manual.

My mother, on the other hand, has never once gone to rehabilitation. Since she started learning yoga at age forty-eight, she's exercised for over two hours a day. I could only conclude that her perpetual, regular exercise had delayed the onset of the condition and slowed her deterioration as well.