

Healthcare

Hawking’s death puts ALS patients in spotlight

Public awareness of the rare disease, known as ‘gradual freezing’, is growing in China, as **Zhang Yi** reports.

The recent death of Stephen Hawking from amyotrophic lateral sclerosis had great resonance in China.

The British physicist was an icon in the country, not just because of his intellect and the visits he made, but also because he was an inspirational figure for Chinese people with ALS, a fatal illness.

Despite being given just a couple of years to live after being diagnosed at age 21, Hawking lived for another 55 years — becoming the world’s longest-surviving ALS patient — married twice and had three children. While his body was in a wheelchair, his mind travelled the universe.

Hawking inspired people across the world thanks to his contribution to science and “his courage and persistence with his brilliance and humour”, according to a statement issued by his children.

During a visit to China in 2006, Hawking made a point of speaking publicly on June 21 — on which Global ALS Day is marked every year — telling Chinese patients, “Physical disability should not stop you from moving forward, just as I do.”

Cui Liying, director of the department of neurology at Peking Union Medical College Hospital, said an estimated 100,000 people in China have ALS, which is known in the West as Lou Gehrig’s disease after a well-known baseball player who had the illness.

Although the average life expectancy of Chinese patients is three and a half years, about half of them die within 30 months, while 20 percent live about five years, and only 10 percent survive for more than 10 years, Cui said.

She added that global research into the illness has progressed slowly, and researchers have not yet been able to determine the cause or identify a cure.

“Although ALS is not yet curable, that doesn’t mean it cannot be treated. Treatment refers to not just extending people’s life spans by the use of drugs, but also careful nursing, which is important to reduce pain and maintain a good quality of life,” she said.

“We have found that the average life span of patients in China is rising as a result of better medical treatment and nutrition, but we haven’t done a thorough survey to prove it.”

Though patients’ living standards have risen during the past decade thanks to better public awareness and improved medical care and insurance, it is still a long way from providing quality of life and dignity.

Degeneration

“In China, ALS is known as *jiandong*, or ‘gradual freezing’, which is an apt description of how the disease develops,” Cui said. “The patient’s muscles gradually become weak, limit-

ing their activity as though they are freezing.”

Medically, it is the progressive degeneration of the motor neurons that eventually leads to death, she said.

The technical name provides a precise explanation of the illness. In “amyotrophic”, the “a” refers to “no”, “myo” means muscle, and “trophic” is “nourishment”. When muscles lack nourishment, they atrophy or waste away.

“Lateral” identifies the part of the spinal cord where the nerve cells that send signals to the muscles are located. As this area degenerates, it leads to “sclerosis”, or hardening.

Clinically, ALS usually starts with muscle atrophy in the hands that gradually develops into limb weakness, and eventually patients lose the ability to speak, eat, move or breathe, Cui said.

In theory, patients with advanced ALS can survive by constant use of a respirator, but that can result in complications, including lung infections and blockage of the airways by sputum or even saliva.

“The cruelest part is that the patient’s feelings, emotions, and cognitive functions are all normal, and they have to watch themselves dying step by step. They can’t scratch a place that itches or cry out when they are in pain,” Cui said.

“In China, the average onset age is about 52, so the majority of patients are middle-aged; the family breadwinner. They endure great pain inside.”

The World Health Organization lists ALS among the top five fatal illnesses, along with cancer and AIDS.

However, the illness is also designated a rare disease as a result of its low incidence, with between four to eight patients per every 100,000 people.

Cui said few patients receive a timely diagnosis because the early symptoms are not obvious and can easily be mistaken for other conditions.

“The clumsy fingers or weak limbs are ignored by many people, but the disease develops rapidly later and by then it’s too late. Early diagnosis is crucial to delaying the progress of the illness,” she said.

Meaningful existence

Shi Qingfu, who has had ALS for 14 years, is a tough, humorous man who does his best to help and encourage fellow patients.

The 35-year-old “eats” five meals a day. Two are injected directly into his stomach via a feeding tube, but he insists on chewing and swallowing the other three to stimulate his throat and stomach muscles.

After breakfast, Shi sits in front of his compute to answer questions from other patients or write about his own experiences.

His mother has to help by



Shi Qingfu, who has amyotrophic lateral sclerosis, aka ‘gradual freezing’, takes a walk with the help of his mother in 2014. WANG CAIYUN / FOR CHINA DAILY



The late Stephen Hawking, who was the world’s longest surviving ALS patient, in March, 2015. JOEL RYAN / INVISION / AP

placing his hand on the mouse every time. He can only move one of his middle fingers, and it takes all his strength to click the mouse. Sometimes his head lolls because his neck is losing the ability to support the weight.

However, no matter how difficult his “work” becomes, Shi insists on doing it because he finds a meaningful world on the internet.

In 2005, when Shi was a jun-

ior student, he started to feel a weakness in his fingers that meant he couldn’t hold a pen. The diagnosis of ALS the following year was a bolt from the blue, given his supposedly promising future.

He overcame many difficulties to finish university, but since then he has stayed at home in Hengshui, Hebei province. Having once been desperate in the face of the fatal illness, his optimism and



I chose to use my knowledge to help other patients because few people travel this road and it requires courage to join in. If everyone did something, ALS patients could live better lives.”

Shi Qingfu, who was diagnosed with ALS 14 years ago

courageous attitude have gradually calmed him down.

His name online is Shitou, or “stone”, which is the literal meaning of his family name and also describes his steadfast personality.

His friends hail Shitou as an ALS “encyclopedia” because he tries to learn as much as possible about the illness and records the changes in his own body.

Linking theory to practice, he uses his personal experiences to help other patients.

Over the years, he has answered more than 10,000 queries from patients and their families on forums, websites and social media. He tries to encourage them with humorous remarks.

“I have made many friends

through the internet. We share the same experiences, so many have been in touch. It makes me realize the value of my existence,” he said.

“Life is about constantly learning and choosing. I chose to use my knowledge to help other patients because few people travel this road and it requires courage to join in. If everyone did something, ALS patients could live better lives.”

Melting hearts

Faced with such a debilitating illness, many patients in China lack the strength to fight back, especially as until recently ALS was little known in the country.

In the West, ALS has been known for many years. In addition to Gehrig, the baseball player, the global fame of Hawking and the Ice Bucket Challenge in 2014 also helped to raise awareness globally.

The past decade has seen improvements in China, with greater social awareness and improved healthcare, according to Zhang Yanling, head of the Chinese Medical Doctor Association.

In 2005, the association established a charity program called “Melting the Frozen Heart”, which aims to improve the quality of life of ALS patients and raise awareness.

“A support system, involving people from different sectors of society, has taken shape during 13 years of effort,” Zhang said.

About 100 neurological experts from 20 hospitals are voluntarily engaged in patient consultation and educating people about the illness.

Zhang added that the association has received donations totaling more 60 million yuan (\$9.5 million) from businesses such as pharmaceutical companies, respirator manufacturers and makers of eye-tracking equipment that allows patients to read computer screens.

“Media exposure has also greatly raised public awareness,” he said.

“Reporters use their pens and cameras to convey patients’ needs and their touching stories,” he said.

“The most important part is the patients and their families who struggle a lot to fight this rare disease, impressing us and teaching us a lot.

Wang Zhenhua, director of the program, said ALS is becoming better known in China.

“When I searched for information about the illness on a Chinese search engine in 2005, there were fewer than 10,000 results, but now there are more than 5 million, so public awareness has certainly been raised,” he said.

“Last year, medication for ALS was included in the national medical insurance program as part of improvements in the conditions for drug use for rare diseases,” he added.

“However, more efforts still need to be made to help patients receive timely treatment, understand the disease in a scientific way and live dignified lives. We hope greater efforts will help us to melt more frozen hearts.”

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FIRST PERSON

This illness shows me how precious life is

Pang Jihong, 47, from Shandong province, cares for her 46-year-old husband, who has amyotrophic lateral sclerosis.

When my husband’s illness was confirmed in 2015, I couldn’t control myself. I burst into tears in the toilets of Peking University Third Hospital. After, I put on some lipstick and pretended to be calm.

The same day, we met another ALS patient. He almost collapsed when he heard his “death sentence”. My husband, an optimist, comforted him for almost an hour, and they both laughed.

How brave they were to

laugh at death. Touched and encouraged, from that moment I was determined to face life’s hardships with my husband.

During our stay in Beijing, I accompanied him around the capital. At the time, he could walk with my help. I thought “Let me be his crutches in the future”. As long as he could sit in a wheelchair, I took him around.

Our daughter was preparing for the college entrance examination, so I told her that her dad’s hips hurt from playing basketball and he had to use a wheelchair.

I hid my husband’s condition from my parents-in-law and other relatives. We only

told them the news at a family reunion dinner after our daughter was admitted to her dream university in July 2016.

In the months of shouldering the burden alone, my hair started going gray. I want to look pretty, so my hair can be dyed, but how can my husband’s illness be treated?

He took medicine — both Chinese and Western — as though eating meals, but the disease developed quickly. In November 2016, he had a tracheotomy. Since then, he has been in bed, unable to speak.

My heart bled when I saw him in the intensive care unit. He used to be a strong man, like an athlete, and enjoyed ping-pong and games. Now, he can only move one finger.

He considered assisted suicide because he was concerned about medical costs being a burden on the family. I told him I would not help anyone to give up their life, and that life is both a responsibility and hope. I told him his life is still meaningful to the family.

He uses an eye tracker on the computer to read the news, watch sports and “chat”. He feels happy, which has improved his appetite. He has five meals a day via a tube, taking 500 milliliters at each meal, an increase from the original 300ml. His complexion is healthier, and his hands, chest and back have more flesh.

His illness shows me how

precious life is and how deep our love is. Sometimes I sing and dance for him, or make jokes. When I have to go out, he sends me messages saying he is OK.

Our life is still happy. Although there is no cure yet, we still hope some magic will occur — at the very least, a better way of extending and improving patients’ lives.

I have changed a lot. I now have the courage to support the whole family and can manage my emotions. I even feel younger. The pain inside has been transformed into a power that enables me to be an active person.

Pang Jihong spoke with Zhang Yi.



Pang’s husband in a wheelchair. PROVIDED TO CHINA DAILY