



Steven walking to a hawker centre near his home in Bedok last December. He is a familiar sight in his neighbourhood, where he has lived for 23 years, and people there know about his condition. For example, the "uncle" at the coffee shop makes him teh tarik with less sugar as he has diabetes. Other shop owners keep an eye out for his whereabouts and keep his wife Lai Quen informed. ST PHOTOS: NG SOR LUAN



**What's it like to be in my shoes?  
Steven shares his experiences with experts who treat the condition.**

The clock was ticking. In 1½ hours, Steven and Lai Quen were due to give a presentation to a group of 10 doctors and nurses at Khoo Teck Puat Hospital. They had volunteered to share their experiences of navigating the healthcare system from the perspective of a patient living with dementia.

But back at home, Steven refused to get ready to go.

"If you don't come, it's okay," Lai Quen told him, before proceeding to the bedroom to get changed.

In the past, she would get anxious and stressed whenever Steven was uncooperative before an occasion.

But she has learnt it is pointless to force the issue and risk him getting even more agitated. Instead, she pretends to accede to his wishes.

It usually works. Five minutes later, he forgot he had not wanted to go, changed his clothes and went with his wife.

"I have learnt not to be discouraged by difficult behaviour and find new strategies to manage it," Lai Quen shared with the healthcare professionals.

She suggested that persons with dementia be given a tag to wear when they go to the hospital for appointments, so that staff can look out for them.

Dementia is an invisible disability, she said, so they may be overlooked and become disoriented.

But having a label is too stigmatising, Steven interjected.

Listening intently, Associate Professor Philip Yap, director of the Geriatric Centre, said hospitals could consider flagging the system when a patient with dementia had arrived, so staff know to pay special attention.

Lai Quen also suggested that doctors spend a few minutes talking to caregivers separately during medical consultations. This is because the patient may not accurately represent things to the doctor during such consultations, yet it is not nice for the caregiver to talk over them or correct them and risk embarrassing their loved ones.

**Persons with dementia cope with the condition in different ways. Steven uses humour as a life buoy.**

Patting his ample stomach, Steven announced that he was on a "seafood" diet, one where he was only allowed to "see food".

It turned out that he had been gaining weight as he would go to the market and have char siew rice every day for lunch, having forgotten that he had had his favourite meal just the day before.

Author and dementia advocate Kate Swaffer, who has young-onset dementia, said: "It is clear that Steven uses humour to survive some of the challenges of dementia."

Ms Swaffer, a board member of Alzheimer's Disease International, is the consultant for ADA's Voices for Hope programme. She has trained persons with dementia like Steven and Lai Quen on how to speak up and tell their stories.

Despite having trouble with his recall, Steven's ability to banter or make witty repartee remains.

Ask him serious questions of whether he worries about not being able to recognise his wife one day or of ending up in a nursing home, and he answers jokingly yet meaningfully: "By then, I would not know what is happening, so why worry?"

Ms Swaffer said Steven is using humour less to hide his pain than as an indication that he is becoming more comfortable with himself.

While Steven uses humour as a lifebuoy, Lai Quen copes by throwing herself into work.

She came out of retirement and continued to have a hectic and challenging job at NCS, maintaining the IT systems of government agencies.

"When I get busy, it is good. Working is the biggest way in which I de-stress. It keeps my brain occupied and keeps me sane," said Lai Quen.

Self-care is important if one is to be able to care for a person with dementia, she said.

Their domestic helper prepares healthy salads for lunch so Steven does not venture out to get his char siew rice fix.

When he does go out, he is such a familiar face in the Bedok South area, where he has lived for 23 years, that people in the neighbourhood know what he needs.

The "uncle" at the coffee shop makes him teh tarik with less sugar as he has diabetes. Others, such as the hairdresser, butcher and fruit stall owner, help keep an eye out for his whereabouts as they know of his condition.

Without any top-down directives, it has become a dementia-friendly community, a more caring and inclusive society for persons with dementia and their caregivers. Said Lai Quen: "They look out for him and tell me where they last saw him."

# 'One day, perhaps, I will no longer hear his voice'

From temper tantrums to false accusations, Steven and Lai Quen share intimate details of their struggle

**Steven Lau, 63, and his wife Wong Lai Quen, 62, give a talk to university students about living with dementia. But first, he needs to remember enough to get them there.**

On a weekday last year, the couple made their way to the front of a room filled with students.

Getting from their home in Bedok to King Edward VII Hall at the National University of Singapore (NUS) had its travails.

Where are we going, Steven asked along the way as he drove.

We are going to give a talk on dementia at NUS, she answered.

Seconds later, he asked again: Where are we going?

Once again, she replied, patiently. But by the time he asked the question five or six times in a row, she found herself just mumbling "mmmm" in response.

Furious, he demanded to know why she would not answer him.

Instead of replying testily that she had told him a million times, she just said as calmly as she could that they were going to NUS.

If the scourge of dementia had not struck one of them, it would have been unlikely for them to return to their alma mater some 40 years later to give a talk.

This public talk last November was their second, the first being an interview on radio earlier in the year. That went well, even though Steven could not remember who he was speaking to halfway through.

This time, he stood up, clasping a piece of paper with all the talking points listed for him.

The students planning to put on a play centred on dementia were keen to learn more about the disease.

Steven began: "I was an honours student who did accountancy, so being smart doesn't mean you cannot kenna (get afflicted)."

Later, as his introduction meandered, Lai Quen gently guided him back to the topic at hand by pointing to his sheet of paper.

Perhaps embarrassed that he needed her help, Steven responded in the only way he knew how.

"Oh, my wife wants me to tell you that I used to work as an accountant and then I transferred to mergers and acquisitions."

"Well, my wife wants me to tell you that having dementia doesn't mean the end of the world but what it takes is the children, the loved ones to accept it."

What was meant jokingly bore the bitter irony that he was no longer his own spokesman.

Lai Quen, too, had lost her composure moments earlier.

"My name is Lai Quen, and this is my husband Steven, who has dementia," she said, dabbing the corners of her eyes as the tears came.

Later, she said it was because she never imagined she would have to introduce her husband that way.

Still, she was bravely determined to share with the students the full, unvarnished "truth" of what it means to live with dementia.

She talked about how Steven demanded that her sister move out.

"That was very hard for me. I felt very sad because I was caught between my husband and my sister, but she was very understanding and bore no grudges," said Lai Quen.

She was also frank about the violence that can come with dementia. While on holiday in France in



Steven hosting a Memories Cafe event for persons with dementia, and their caregivers, at an eatery in Jewel Changi Airport last October. He is seen here helping out Mr George Chong, 49, who has early onset dementia, with lyrics to a song the participants are singing. ST PHOTO: NG SOR LUAN



Lai Quen, during the couple's talk to NUS students last November, acting out an incident where Steven had punched her brother-in-law. ST PHOTO: NG SOR LUAN



Lai Quen in tears after Steven presented her with a bouquet of flowers after a sharing session at the National Library last December. ST PHOTO: NG SOR LUAN

2018 before attending their daughter Valerie's wedding, Steven punched Lai Quen's brother-in-law during a heated conversation.

The damage was minimal but witnesses were horrified.

"We were all shocked because he would never do this in the past. But the very next hour, he forgot what he had done and sat next to my brother-in-law at dinner and kept talking to him, as if nothing had happened," Lai Quen said.

She knew she could be honest because Steven would soon forget what she had just said.

It is not easy to have to share such personal details, said Lai Quen. At another sharing session, a caregiver talked about how her husband had been unable to find the toilet in their hotel room, and presented her with his underwear neatly folded the next morning, but full of faeces.

"It is important to give real examples so that people know that dementia goes beyond forgetfulness, but at times our loved ones may be aware and sensitive to it," said Lai Quen.

There had been times in the night when Steven rolled over to her in bed and said he wanted to die.

He never elaborated. Words could not express his sense of alienation and sadness.

**Persons with dementia watch a play on dementia. Do they recall enough to recognise facets of themselves being shown on stage?**

Steven and Lai Quen sat in the darkened theatre of the University Cultural Centre at NUS, alongside 12 other clients and caregivers from the Alzheimer's Disease Association (ADA) one evening in January.

They had been invited by King Edward VII Hall to watch a play titled Don't Forget To Remember Me. It was written by local playwright Haresh Sharma.

The 45-minute play traced the internal transformation of caregiver Janice, whose mother has dementia, as she moved from confusion, frustration and denial towards acceptance of her mother's condition.

Director of the play, Jed Yap, 23,

was more than a little anxious that night, knowing that the play would be seen by persons living with dementia. "Portraying dementia is risky and I don't want to make a mockery out of it," he said, hours before it was staged.

One scene showed Janice breaking down and articulating her wish for her mother to die so that she could move on with her life.

Emotion rose in Lai Quen. She, too, remembered how initially she had wanted Steven to die as she could not cope with the pain and stress. When agitated, he would rain vulgarities on the family and bang the table or door.

It is difficult to love someone when one is always being scolded or perpetually on call, she said quietly.

She recalled one New Year's Eve, when Steven told her she was free to go and watch fireworks with the children while he stayed at home.

Yet, when she was out at the Marina Bay area, she received one text message after another from him, all of them accusatory. They said that

they could go separate ways and divide the property accordingly.

By the time she got home, he was banging doors.

From that day, she became cognisant of another form of loss - her freedom.

"At least he can still shout and bang the table and express himself. One day, maybe he won't even be able to do that; one day, perhaps I will no longer hear his voice," said Lai Quen after the play, as tears welled up, trying to squeeze out gratitude within herself so as to change her perspective about the situation.

Steven seemed to be aware of what was happening on stage. When Janice's mother started repeating her sentences in the play, immediately he blurted out: "Dementia, dementia!"

The play had moved him to acknowledge a secret compartment of grief within him. "I know what the play is talking about because I experience it. But I can't transfer this sadness to others."