

# How dad talked through Parkinson's



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**A** NEW centre at a Bishan Street 13 void deck now offers physiotherapy, art therapy and other services for people with Parkinson's disease. After Alzheimer's disease, this is the second most common neuro-degenerative disease here. About 4,000 people are affected, most of whom are aged over 50, but more in Singapore are now being diagnosed in their 40s.

Doctors usually tell patients and their caregivers that Parkinson's disease is a brain condition that affects the motor functions, causing tremors, immobility, stiffness and poor balance. They like to reassure them that it is not a psychiatric illness.

While all that is quite true, the physical deficits the disease causes lead to a host of neuro-psychological problems.

Most patients experience a cycle in which it is not just their physical agility but also mental energy that fluctuates from "on" to "off", and vice versa, usually because of the timing of their medications. From living independently to becoming progressively more dependent on caregivers, the Parkinson's patient usually goes through stages of denial, panic, anger, helplessness and depression.

Living with a chronic degenerative disease of any sort is hard to come to terms with but many doctors and family members may not quite grasp the patient's first-hand experience of the condition. As such, they may not quite comprehend his exper-

iential challenges.

My father who died seven years ago suffered from Parkinson's. During the years of his deterioration, I often coaxed him into talking about his experience of the illness.

Over the last few weekends, I have finally been able to retrieve the videotapes I made of our conversations and watch them in an attempt to recover a sense of his first-person experience of the adversities he faced.

Dad described to me his cyclical periods of near immobility and mental lethargy that alternated with periods of excessive movement and mental energy.

The periods were quite sharply separated from one another, he said, as if someone turned a switch on or off inside his head at the appropriate time.

In the periods of a day before the medication levodopa restored both movement and clear thinking, his mind would feel "clouded", he said. This upset him no end, for not only could he not move about freely but he also could not communicate lucidly.

The cyclical energetic periods were experienced as a kind of relief from the sharply delineated periods of enervation and ennui.

But the relief that came with each dose of levodopa was never a completely satisfying one, because it came with a frenetic level of activity that felt out of control.

The mobility that came with those periods felt frenzied and artificial, dad said, so his body no longer felt like it was completely his own. He felt that his old - and real - self was "still inside", imprisoned by a new self that irritatingly made its presence known to all and sundry through this disharmonious "outer" body.

Apart from the mobility and balance problems caused by Parkinson's, dad also had tics called dyskinesias caused by the



Patients undergoing physiotherapy at the new Parkinson Centre in Bishan. Most patients experience a cycle in which it is not just their physical agility but also mental energy that fluctuates from "on" to "off", and vice versa, usually because of the timing of their medications. ST FILE PHOTO

levodopa itself.

These involuntary abnormal movements of various forms - the word is made up of the Greek "dys" for difficult and "kinesis" for movement - were never completely resolved by treatment. His dyskinesias were mainly writhing movements of the head and neck, along with his arm being pulled behind the back.

The sustained muscle contractions in these dyskinesias gave dad quite a lot of pain. But most of all, the muscle contractions made him quite angry because the grotesquerie they caused made him physically unable to project the persona of that autonomous, articulate and capable man which

he used to be.

He would try to conceal the dyskinesias and mobility loss. But as his condition deteriorated, the attempts to do so only made things worse. Dad said if he tried to hide his hands by making a fist, so the fingers would stop moving around, say, his contortions would become more pronounced.

Nevertheless, he tried to organise his life around the four times he took his levodopa every day. He could not just get up at eight o'clock, say, and head straight out of the house to join his retiree friends for taiji. Instead, he had to sit in his armchair and wait for the pills to take effect before he could move.

The brain wasn't unreflectively or spontaneously telling the body to do things as before, dad said. He had to consciously tell himself to put one foot in front of the other, step by step. Sometimes, while walking, he would freeze and stumble.

Mind and body were no longer united, he said, and routines or activities had to be planned around his symptoms and medication, which sucked the oxygen out of his *joie de vivre*.

Also, the levodopa sometimes didn't quite work, so dad felt that the pills were in control of his life. If the pills did not work, he would just have to sit there, waiting fecklessly for the next dose hours later

as he could not overdose on it.

Eventually, he just stopped meeting his buddies. But to the very end, dad was always talking - whenever he could - about who he really was and the unreal disconnect between body and self. For him, these concerns were as important as the immobility, tremors and dyskinesias.

This was dad's lived experience of Parkinson's, something the physician and family caregiver might want to spend time on with their own patient. Talking about it could help a patient achieve a modicum of control over his predicament.

I hope it did for dad.

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