

MY JOURNEY WITH PWID:

# Happee Hearts MOVEMENT

## A CHANCE ENCOUNTER

My encounter with persons with intellectual disability (PWID) occurred by chance. At the age of 17, I decided on a whim to volunteer my time and thus wrote to the National Council of Social Services requesting to volunteer in an orphanage. They replied promptly and said with apologies that the orphanages did not require my services then, but asked if I would like to work with the intellectually disabled instead.

I thought to myself, "why not?" and that was how I landed up going to an activity centre for PWID on a sunny Sunday afternoon. Nothing in my life up until then could have prepared

me for that first encounter. I stepped into the centre and was petrified. Everything about the "trainees" (as we call PWID) was unlike anything I had experienced. They looked, behaved and even sounded different from what I was used to. In fact, I was so frightened, I decided that I would leave after the session and never return after being there for just ten minutes.

Eagerly looking forward to the end of the session, I breathed a sigh of relief when it was finally time for the trainees to go home. Their families came to pick them up and the trainees waved goodbye. I too waved to them, thinking it was "goodbye forever". Yet for no apparent reason,

an unforeseen feeling came over me. As I watched the trainees leave with their families, saw the bright smiles on their faces and listened to their shouts of "thank you", "bye bye" and "see you next week", I suddenly felt a lump in my throat.

Something inexplicable and unexpected touched me at that moment. I decided there and then, that I *would* return. And I did, for the next six years, even through medical school. I stopped volunteering for a while after graduation, as I got lost in the frenzy of work as a junior doctor. But in 2010, I felt a strong prompting to volunteer again and I returned to the organisation, this time as a doctor.



## HEALTH CONCERNS FOR PWID

Together with the Movement for the Intellectually Disabled of Singapore (MINDS), we organised the first health screening for PWID in 2011. The first screening, though simple, was very much appreciated by the attendees. We knew that the need was great, so my husband, Liam, and I worked with MINDS on catering to the specific needs of PWID and their families, and strived to improve on the screenings.

By 2013, the screenings had become regular volunteer-run events during which we held general and dermatology consults, first-aid workshops, and even cooking and nutrition workshops conducted by dieticians. In 2014, we extended these health screening events to other voluntary welfare organisations, namely the Association for Persons with Special Needs and the Down Syndrome Association.

Over the years, we have picked up many medical problems but sadly, there were few appropriate places to refer them to. There were multiple obstacles to PWID attaining good quality and holistic healthcare, particularly as they age. These include communication barriers, ageing caregivers and a lack of knowledge and awareness among healthcare professionals, just to name a few.

The Adult Neurodevelopmental Service at the Institute of Mental Health manages the behavioural and mental health problems encountered by this population, while paediatricians manage the medical needs of children with developmental problems. However, there is no medical set-up in Singapore that caters specifically to the complex physical healthcare, functional and psychosocial needs of adults with intellectual disability.

As the work grew and time passed, I asked myself this question, "Where are we headed with this?"

## JEFFREY

It was at this time that I met Jeffrey, a 42-year-old boy with Down syndrome who had been attending a sheltered workshop for many years, but had abruptly refused to leave his home. Everyone was puzzled. His training officer, psychologist and therapists from the sheltered workshop visited him at home and encouraged him to head back to the centre but he refused. His family tried all means and ways to cajole him out of his home, which was also to no avail. Jeffrey is a gentle and loving boy and he had enjoyed going to work tremendously. No one could understand why this had happened.

At the request of a friend from the sheltered workshop, I visited Jeffrey in his home and spent some time examining and speaking with him. There, I discovered that there were multiple factors contributing to Jeffrey's refusal to go back to work: his osteoarthritis, deconditioning and a lack of confidence, among others. His family and I decided to address these factors one at a time. A few weeks later, I was once again with Jeffrey in his home. By then, his arthritis was much better and he knew me as his doctor.

Miraculously, on that glorious sunny afternoon, Jeffrey stepped out of his home for the first time in more than two months and we brought him back to the sheltered workshop that very day. Greeted warmly by his training officer and friends, he eagerly showed me to his work station.

*His family was in tears, and so was I.*

The next morning, his sister sent me this message: "My brother got up this morning at 5 am, packed his bag and went off to work." This is a message I will never delete.

Some time later, Jeffrey developed a medical problem that required a surgical procedure. His family was conflicted about proceeding with it for fear of breaking his routine and work schedule again. Jeffrey also disliked visiting doctors and every visit to the clinic or hospital would distress him greatly.

I spoke to his family at length and we decided to work together to prepare him for the hospital visits. By then, Jeffrey knew me well. I explained that we needed to get him to the hospital and that there was nothing to fear, for he would be seeing my friend; and his family and I would be there with him.

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## PROFILE



TEXT AND  
PHOTOS BY

## DR CHEN SHILING

Dr Chen Shiling is trained in internal medicine and currently works with the geriatric population and also with adults with intellectual disability. She loves travelling, trekking, running and always enjoys a good cup of tea. One of her favourite sayings is from the movie *Up*: "Adventure is out there!"

*Footnote:*

*Happee Hearts Movement is looking for medical professionals to join them for their health screening services for PWID. For more information on the movement, please visit their facebook account (<https://www.facebook.com/happeeheartsmovement/>) or register your interest at <https://www.sma.org.sg/smacades/>*

### Legend

1. A typical health screening session with the beneficiaries
2. With Jeffrey, the co-founder of Happee Hearts Movement
3. Volunteers with Happee Hearts Movement



"Will you trust me?" I asked Jeffrey as I held his hand. He looked right into my eyes, nodded slowly and smiled. At that moment, my heart swelled with an emotion I could not describe and I felt tears come to my eyes.

Suffice to say, thanks to the kindness and accommodation of a wonderful surgeon, the consultation and procedure took place smoothly with minimal trauma and distress for Jeffrey. After his discharge from the hospital, Jeffrey had to stay off work for more than two weeks as the wound took time to heal. My husband and I dressed and cared for his wound on a regular basis at home.

Gradually, we prepared him for his return to the sheltered workshop, praying that he would slip back into his usual routine. It turned out that we had nothing to fear; on that morning, Jeffrey simply packed his bag and took the bus to work.

## THE MISSION AHEAD

Prior to meeting Jeffrey, I had wondered if there was more I could do for adults with intellectual disability. After meeting him, I knew that there is much more that can be

done. In 2015, with Jeffrey as a co-founder, I set up the Happee Hearts Movement, a non-profit company which serves as a platform to advocate good quality healthcare for adults with intellectual disability. I have also started a home medical service to cater to the medical needs of PWID who are homebound.

My hope is that in time to come, we will be able to provide good quality, comprehensive and accessible medical services for PWID throughout their adult lives. It is crucial to also support the families and ageing caregivers, as their children or siblings transition into adulthood and old age.

Just like Jeffrey, each and every person with intellectual disability has the ability to contribute to our society in both tangible and intangible ways, and all should be done to support them and their families as they navigate the often stormy waters that come with the diagnosis of intellectual disability. As healthcare professionals, I believe that our role is to bring health to their lives, in a compassionate and loving manner, to enable and empower them as they soldier on in their journey of life. ♦

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