

Living WITH Frailty

A CAREGIVER'S PERSONAL JOURNEY

Text and photos by Dr Joseph Leong

By 2030, one in every four Singaporeans will be aged 65 years and above. Frailty after 65 – becoming weaker and living with functional decline whether in strength, eyesight or hearing – is something that many Singaporeans will experience. It boils down to either overcoming it with preventive strategies or struggling with the choices and its consequences, and being overcome instead. Here, I share my personal experience as a caregiver, looking after my ailing father.

Early retirement and re-employment

My father was born in 1940 to a fairly well-to-do Hainanese family and had an overseas education. He trained as a chef in Europe, worked in several hotel kitchens and finally ended up running his own coffee shop.

He decided to retire when he was around 55 years old, after an unforeseen incident foreclosed the coffee shop. The next two years saw the onset of depression as he was unprepared for retirement after having worked more than 100 hours a week. Initially, the family thought that he would just help out around the house – something that he had rarely done in the past. However, he would often fall asleep after meals and would not find joy in anything that he does at home. He became increasingly grumpy and began slowing down mentally too.

That was when I suggested that he did some part-time work. When my father started working in a nearby Pizza Hut restaurant, he became “alive” again. He was so happy to receive tips from generous customers and even invited me to eat at Pizza Hut with the vouchers he received with his payslip. Everyone

started calling him the “Pizza Hut Uncle” after he was featured in a Pizza Hut poster and after several years, he became a full-time staff.

Retirement

One day, he slipped and fell while walking home in the rain. He twisted his ankle and it was badly swollen. He insisted on seeing a Chinese physician although I strongly recommended that he visited a doctor to get an X-ray. He went for several sessions with the Chinese physician over a couple of months. Though the swelling subsided, his ankle became deformed and his gait became unsteady. Even then, he still refused to see doctors in the hospital because to him, it was a waste of time and money.

After he finally retired from Pizza Hut at 65 years old, I asked him to go for medical check-ups and he was more willing. He was found to have spondylosis both in the cervical and lumbar region. Physiotherapy was recommended but once again, he felt that it was a waste of time and money.

In 2010, when he was 70 years old, he went for coffee by himself at Marina Bay Sands SkyPark. He declared to the family that it had a wonderful view, hinting that he was still very independent and could do things on his own, in his way. However, he suffered more and more falls as he grew stiffer with unsteady gait. Finally, my mother was so upset with his repeated falls that she confined him to home in 2013. His moodiness returned with a vengeance with frequent quarrels and shouting.

My mother suffered from severe caregiver stress and fatigue. She needed respite care urgently and she left my dad



to our care while she went overseas. Both my sister and I had to take urgent leave to help out. There was talk about placing my father in a nursing home.

Wheelchair = mobility

I decided to persuade my father to use a wheelchair. Many people of my father's generation, including him, have the impression that wheelchairs are for the disabled and handicapped – equating sitting in a wheelchair to admitting that you are crippled or disabled.

It was not going to be easy but my plan was to bring him out to the Singapore Zoo and River Safari with his grandchildren. I told him that I needed his help to sit on the wheelchair rented at the Zoo, so that we can roam around easily. Although reluctant, he recanted.

It also helped that since the little ones had not seen a wheelchair at home before, they all wanted to sit on grandfather's lap and be pushed along too! We had a really fun time and shared wonderful moments of joy.

A few days later, I also managed to persuade my father to use the spare wheelchair in church, where there were also wheelchair-friendly toilets. His friends in church finally got to meet him and many came up to greet him warmly. He felt accepted and likewise came to accept the wheelchair as a mobility aid. My father even attended an inter-religious harmony walk in his wheelchair.



Even though my father's mood and mental state improved and he started attending various functions outside the confines of the house, he was getting physically weaker over the years. My mother and I hunted for various day care centres in 2015 but my father refused for various reasons – he did not understand that my mother needed a respite from daily caregiving.

Increasing frailty and near death

My father became very sick from infection and nearly died in September 2016. My brother flew back from the US to help us out. My father also started showing signs of dementia after his delirium cleared, with increasing irritability and temper tantrums when demands were not met. He was also confused about daily routines and his visitors. Pastors visited him and prayed for him and our family. Everyone was praying for peace at home and we even set up a WhatsApp group – “Peace at Home” – to support one another through prayer and practical help.

Thankfully, my father survived the acute illness but as he was greatly weakened, the family scrambled to get a maid before his discharge from hospital. We were grateful for the extra time given when he was transferred to a community hospital.

During one of the hospital visits after church, I saw a vision of my father – young, handsome, restored and smiling. I realised that it was just like his wedding photo. I shared this with the family and they were greatly encouraged. We subsequently renewed our faith and unity to look after my father to the best of our abilities at home, with restored family relationships and less disagreements about care arrangements.

Once, my youngest daughter, Trinity Faith, went to play with my father's hair. Instead of scolding her, my father started to giggle and laugh – just like a child. My family believed that although the dementia is still there, my father is “happily demented”.

Personal thoughts

Frailty – growing old and needing care – encompasses various aspects of support.

I realised that one's decisions impact not just the individual but the family and community as well. The decisions that my father made, be it to settle for early retirement or to not seek proper treatment for a fall, have impacted the family.

However, we are not alone on this journey. The wider community, such as our church in our case, offers practical help as well as emotional and spiritual support. Even the availability of wheelchairs and wheelchair-accessible toilets and exhibitions at places such as the Singapore Zoo, Gardens by the Bay and museums, made a big difference.

As our family matures as a more caring family, we learnt to make more joint decisions rather than let my father make them alone. Yes, we still respect his autonomy, but being the eldest son, I have had to mediate between him, my mother, my younger sister, my younger brother in the US, as well as my own emotions growing up as a latchkey child who had two working parents. Our faith as a family helped us through challenging times when we are reminded to love and serve one another. Likewise, we also discussed the topic of dying well.

It is also wonderful that we can focus on possible solutions and options such as step-down care and day activity centres, mobility aids, wheelchair-friendly buildings, dementia-friendly businesses, as well as a future City for All Ages.

Living with frailty is beyond just a physical healthcare issue. I hope that this article highlights a more holistic picture of the mental, emotional, social and spiritual aspects of ageing in the community.

Although there is no cure for dementia and death, there is hope for families to stay united and caring in the process.

Society can also progress towards becoming a more inclusive community. The Government has put in both time and money to develop programmes and services for active ageing. I believe that it is our duty as healthcare professionals to get to know all the various initiatives and make recommendations beyond just medications, so that our patients can enjoy happier and healthier living. We can also speak up to highlight concerns and take actions to build a better Singapore! ♦

Further readings

1. *Creating Moments of Joy for the Person with Alzheimer's or Dementia: A Journal for Caregivers 4th Edition*, Kindle Edition. Available at: <https://goo.gl/YUDYp>.
2. Jolene B. *Creating Moments of Joy*. Available at: <https://goo.gl/21H2ed>.
3. *Living Matters. Advance care planning*. Available at: <https://livingmatters.sg>.
4. *Agency for Integrated Care. Singapore Programme for Intergrated Care for the Elderly*. Available at: <https://goo.gl/5h6zoU>.
5. *Ministry of Health. \$3 billion action plan to enable Singaporeans to age successfully*. Available at: <https://goo.gl/Nuk7fF>.
6. Mohandas V. *Singapore's first active ageing hub launched*. Channel NewsAsia 2016 Dec 3. Available at: <https://goo.gl/liLhWl>.
7. *People's Association. Active ageing*. Available at: <https://goo.gl/kkWCCW>.

Legend

1. A family photo taken at the Gardens by the Bay
2. My father in a wheelchair with the excited young ones

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