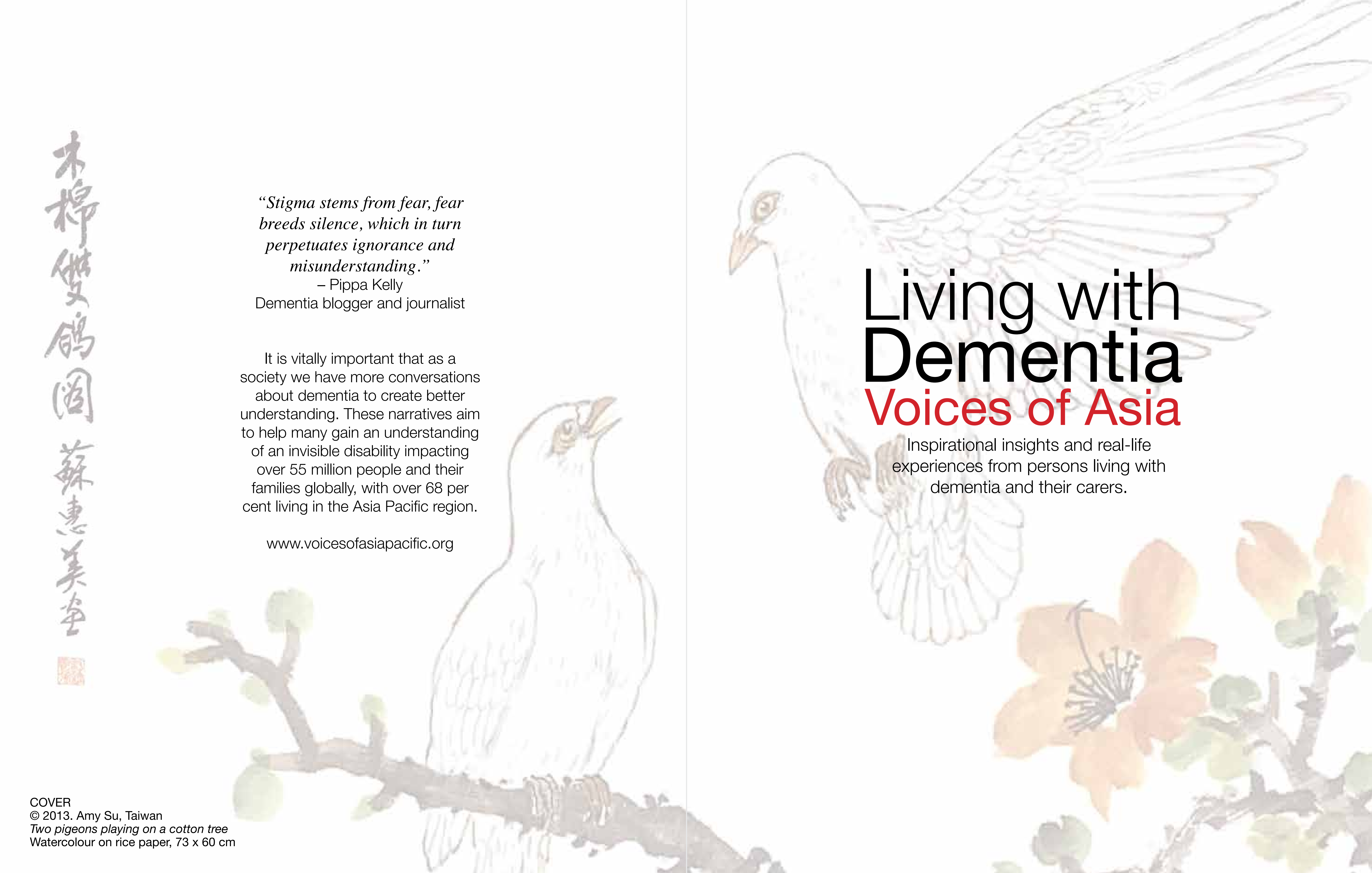


"Stigma stems from fear, fear breeds silence, which in turn perpetuates ignorance and misunderstanding."
– Pippa Kelly
Dementia blogger and journalist

It is vitally important that as a society we have more conversations about dementia to create better understanding. These narratives aim to help many gain an understanding of an invisible disability impacting over 55 million people and their families globally, with over 68 per cent living in the Asia Pacific region.

www.voicesofasiapacific.org

COVER
© 2013. Amy Su, Taiwan
Two pigeons playing on a cotton tree
Watercolour on rice paper, 73 x 60 cm

Living with Dementia
Voices of Asia

Inspirational insights and real-life experiences from persons living with dementia and their carers.

I want to be free

How you choose to see me,
treat me, talk about me
affects my right to freedom
and my right to live
a meaningful life on my own terms.

– Emily Ong
eBook Project Lead

FOREWORD

I want to tell you from my experience that the dementia journey can be delightful and fruitful,
– Miki Sato, Japan, diagnosed with dementia at 48.

This book is wonderful. It sets out to demonstrate that although a diagnosis of dementia can be a shock to the person living with it and their family, there are silver linings everywhere. It demonstrates without doubt how life with dementia is well worth living and that you can enjoy every minute of it. Each word of this book is a droplet of wisdom, reminding me of the fairy tale of Hans Christian Andersen. An entire universe in one drop of water. And just like that there is an entire disintegration and reconstruction of each life in these wonderfully written stories.

The juxtaposition of the voices of people living with dementia in many different parts of Asia and people caring for people living with dementia is beautifully done. Many carers speak candidly of the many challenges facing them: lack of information; difficulty finding help; wishing governments provided more services. Everybody remarks on the joy of finding an Alzheimer's association and support groups full of people living the same experience.

It turns out I am not alone. Getting to know these people is like having a new family.
– William Buntoro, Indonesia, diagnosed in 2018.

The book does not shy away from the difficulties, the challenges, the exhaustion, at times the despair. What also comes out powerfully is the stigma and the lack of information all over Asia.

Sadly, none of the medical practitioners advised caregiving as a powerful tool – even though, in the absence of any medication, it was in fact the only tool available to us.
– Bina Berry, India.

There are powerful and recurrent themes. The realisation of the need for families to rethink and relearn their relationship with their loved one living with dementia, to discover new knowledge about them, crops up everywhere in the book.

Dementia does not change a person. It brings them back to their core memory and we help them by finding out how they chose to be understood and loved.
– Siti Nadzirah Hi Abdullah, Brunei Darussalam.

So does, sadly, the awful feeling of being a burden on one's own family from people who have been diagnosed. More powerful than anything else is the fact that each individual's story and perspective is so different. It reminded me powerfully of the work of Tom Kitwood, who first articulated the concept of people-centred care. Truly the circumstances of each writer are unique and remind you of the unpredictability of life. Primary carers passing away before the person they care for, doctors who despite all their training are caught by surprise by the complexities of dementia care, a couple both diagnosed with Alzheimers at the same time.

But the hope that comes from this book is even more powerful. Many remark on the importance of hearing advocates speak of their own journey with dementia and how that inspired them. One person even speaks of how early diagnosis and the advice of the doctor on risk reduction, slowed down his progression of the disease enough to stop taking medication.

I must thank Emily Ong, advocate, one of the main people behind this book, and a board member of ADI for asking me to write this introduction and enabling me to stop all I do for a while and really absorb myself in these stories. I think I am a better person for it and these voices convince me even more of the importance of our mission, of the need for us to advocate at the highest level for government support for families and at the simplest level to empower and grow the grassroots organisations that give all the contributors to this book a new lease of life. Many contributors mention Alzheimer's Disease International and our wonderful members in their stories and how our work has transformed their life. This is what keeps us doing what we do.

What this book does matters. Some of the people writing are sharing their story for the very first time. We owe them an everlasting debt of gratitude for opening their soul and allowing us to find inspiration and spiritual nourishment from their stories.

Paola Barbarino
Chief Executive Officer
Alzheimer's Disease International

28 July 2023

MESSAGE

When my late mother Madamme Tien was first diagnosed with dementia in 2009, I found myself struggling. I didn't know how to help her. I knew virtually nothing about dementia and even less about how to make each day special.

The experience of taking care of her gave me the inspiration to establish Alzheimer's Indonesia in 2013, set up a support group as a platform for people with dementia and family care partners, where their voices would be heard and where they could seek information, education, training, networking, access to referrals, post diagnosis support and other resources. Moreover, my caregiving journey gave me an opportunity to support other members joining the Association, as well as those in the Asia Pacific region under the umbrella of Alzheimer's Disease International (2016). My late mom has been my source of inspiration in improving quality life of people with dementia and their care partners (including intergenerations) around the world. Mommy Tien passed away in 2017 but her legacy continues #ForeverGrateful.

Through my role at Alzheimer's Disease International, I learned about the "Voices for Hope" programme, a Dementia Singapore initiative that aims to empower persons living with dementia and their care partners, encouraging them to share their stories which led me to cross path with Emily Ong in 2018. This initiative created a ripple effect, whereby a group of people with dementia could step up, get involved in, and maximise their potential including contributions to the 'Voices of Asia' eBook.

This eBook underlines the importance of the voices of people with dementia and family carers in Asia. Currently, there are 55 million people in the world living with dementia. Although 26 million are in Asia, their voices are seldom (if ever) heard. It is important that we understand the journey of a person with dementia, their carers and families – both before and after diagnosis – as this will lead to a greater understanding of how we can best contribute to improvements in the quality of life for the whole of society.

My salute and huge appreciation to my dear kindred spirit friends and colleagues: Emily Ong, Datin Jacqueline Wong and Li Yu Tang who have initiated and spearheaded this amazing and inspiring eBook, a collection of 20 narratives from persons with dementia and their informal care partners in 13 countries in Asia. This includes 6 stories from Southeast Asia, 3 from South Asia and 4 from East Asia. Thank you for sharing your stories. They will inspire more people around the world. The 'Voices of Asia" eBook is an authentic collection of narratives by people with dementia and their informal carers, including family members. It is a great inspiration and it is a dream come true. But more than anything, this eBook is a gift and a true celebration of life. *Proficiat!*

DY Suharya
Regional Director – Asia Pacific, Alzheimer's Disease International
Former carer for beloved mom

dy.suharya@alzint.org

PREFACE

Living with dementia or caring for someone with dementia can be a lonely journey for the person concerned. As a person living with dementia, you not only have to learn to accept decline and changes are the new norms and inevitable parts of your life, but you also need to shoulder the cultural stigma that comes with the diagnosis. Often it is the stigma, systemic prejudices and discriminatory structures that do more harm and damage to the person's quality of life than the disease itself.

The infringement of the right to autonomy and independence is rampant among people with dementia, affecting their self-esteem and confidence. While older people with dementia can experience a "double stigma" of dementia and old age, younger people with dementia experience the risk of being marginalised in terms of inappropriate care and lack of social support. Additionally, the stigma of dementia can contribute to social exclusion, which in turn can lead to social isolation issues such as depression.

As a person with dementia, I experience stigma and discrimination firsthand but also see the adverse impact on families, particularly those from minority groups and/or with low and middle socio-economic status. There are over 38 million people with dementia in the Asia Pacific region, with the majority in the low and middle-income countries. Stigma and discrimination against people with dementia are both pervasive in these countries due to a lack of dementia awareness, and a cultural context in which not only is the existence of dementia denied; rather it is assumed to be a natural process of ageing and not a result of a brain degenerative disease. Furthermore, the inadequate preparedness of the healthcare systems in resource-poor settings worsens the situation.

Together with my two friends: Datin Jacqueline Wong (Brunei Darussalam and Malaysia), former carer and Hon. Advisor to demensia Brunei; and Li Yu Tang (Taiwan), former Secretary-General of Taiwan Alzheimer's Disease Association, we initiated the eBook project to harness the collective power of narratives and create durable social change in dementia. Currently, there are few, if any, dominant narratives from Asia, and in most countries, the voices of people with dementia are neither recognised nor heard.

This eBook collection is intended for you, whether you are a person with dementia, or a close friend or family member of someone facing dementia. You may be a policymaker seeking to understand the lived experience of those impacted by dementia or perhaps you are a concerned citizen of the world who is wanting to be a dementia changemaker. Whatever your situation, we believe "Voices of Asia" can extend power to those living with and affected by dementia and nurture a shared hope and vision of a better quality of life that respects the rights and dignity of the person with dementia.

Throughout the eBook you will come across recurrent themes, including the benefits of having a support system and knowing you are not alone. We hope such narratives will inspire you to advocate for change in attitudes towards dementia; raise dementia awareness and break the silence on this subject; challenge harmful narratives to reduce stigma and discrimination; create a sense of comfort in talking about dementia; and work in partnership with those with dementia to tackle this global public health issue.

I would like to thank the Project Core Team for their constant support and belief in my abilities; and the publishing team of this eBook, including Trish Amichi (Australia), for her editorial guidance and input. I also want to thank Paola Barbarino, CEO of Alzheimer's Disease International (ADI) and DY Suharya, Regional Director – Asia Pacific Region of ADI and the participating ADI Member Associations for their support in this project. But most importantly, I thank the persons with dementia, their families and their care partners for their great generosity – for coming together with us and consenting to their stories to be available in a book intended for a wide, wide audience.

Emily Ong
Li Yu Tang
Jacqueline Wong
Living with Dementia: Voices of Asia
eBook Project Core Team

www.voicesofasiapacific.org

BRUNEI DARUSSALAM

When even the brightest flowers failed...

The late Hajah Zainab Abdul Rahman (83) was diagnosed with dementia at 70. Her story is narrated by her grand-daughter, Siti Nadzirah Hj Abdullah.

As I was growing up, it seemed to me that *Nenek* was the perfect homemaker. She was the epitome of a stay-at-home wife. She cared for her husband, her children, her neighbour's children, her children's children, and literally, any other child who needed to be fed or looked after. *Nenek* was an award-winning baker, entering and winning all the baking and cooking contests in the Belait District. My mother, *Nenek*'s second daughter and third child, would always recall the day *Nenek* travelled over 100 km in a bus – all the way from Kuala Belait to Bandar Seri Begawan – a tiered cake on her lap. This cake won her a $1,000 cash prize. With the money, she bought herself a gold chain bracelet, which she wore until the end of her days. She was also a fashion designer in her own right, designing and sewing her daughters' wedding dresses, curtains, bedspreads. You name it – she could make it with her own two hands.

Nenek was everyone's safety net. Her beloved husband, my *Atok*, had named her 'Rose', for her gentle and loving demeanour. Her nieces and nephews would call her *Mama*. Later, her friends and guests from the Middle East would do likewise. No one she encountered would be spared her love.

As soon as the school holidays started, her grandchildren would be over at her house in a flash, because we knew that we would be fed, loved, doted on, and be free to do anything we wished. We would frequently find ourselves in the kitchen helping *Nenek* bake; outside – helping her water her flower garden; or in her room – pulling out her grey hairs while a P. Ramlee movie played in the background.

Nenek was trilingual and she loved studying. She was fluent in Malay, English and Arabic. She reached her peak at 50, delving into a variety of hobbies and exploring a wide range of interests. She even took Arabic and Islamic Medicine classes and, in doing so, made many friends from across the world. This was undoubtedly a great achievement for a homemaker in the 90's, let alone for someone lacking internet, or computer skills. A determined lady, *Nenek* took driving lessons at the age of 60 – just in case she ever needed to drive *Atok* to the hospital in an emergency, but mostly so she could drive herself to her classes and meet with her friends.

Although a time would come when *Nenek* would fall ill and slowly lose her memory and her great capabilities, her smile, her love of P. Ramlee, and for her loved ones always stayed with her. The decline began in 2003 when a fall, caused by a mild stroke, sent her into a coma. After recovering from that, she stopped going to her classes. She also stopped baking, instead instructing her husband, my *Atok*, to make her specialities, including around the next few Hari Rayas (or Eid) celebrations.

Over the course of the next 10 years, we could tell that *Nenek*'s memory was progressively failing her. It started with the little things, like being unfamiliar with distant family members and friends, before progressing to the loss of recipes for her 'greatest hits.' In 2011, she was diagnosed with dementia. Her vulnerability led to role reversal and *Atok* became her primary carer, assisting her with medications, meals, maintaining her personal hygiene and taking care of everything else she needed.

Over the next decade of her life, *Nenek*'s confusion and disorientation would get the better of her. Sitting in the living room of her 30-year-old house, she would constantly ask us to take her home to be with her father. At first, we would try to explain that she was already home; that her father had passed away decades ago. Over time, we realised that explaining the facts only served to overwhelm her. So, we would lead her to her bedroom and sit her next to *Atok*: this being where she felt safest.

There came a day when both my grandparents were no longer fit to stay in their own house, far away from their children. We packed their essentials, set up a cosy room for them in our house and coaxed them to stay. They had agreed to do so for a week. The week became a month; the month became 4 years. As *Nenek*'s dementia progressed further, she began to mistake *Atok* for her father, and at times would fail to recognise him at all. There would be days she would be resting in bed with *Atok* when, in a split second, she would freeze. She would ask him to move away or leave the room, believing that she wasn't married and frightened that she would be caught in bed with a man. It took some time for my doting grandfather to understand that he shouldn't get offended, as it was simply a case of *Nenek*'s dementia taking over.

As *Atok* grew too old to care for her, my mother, who had been a full-time mother and executive at one of the most notable corporate organisations in the country decided to retire and become *Nenek* and *Atok*'s full-time carer. Now that *Nenek* was living with us, her disorientation became even more noticeable. She spent her days folding and refolding her laundry. She prayed more than 5 times a day, and at every opportunity, she asked whoever

Her beloved husband, my *Atok*, had named her ‘Rose’, for her gentle and loving demeanour.

was present to take her back to her father. There would be long periods when she would be upset. We knew she was unhappy because she would start reprimanding everyone in English. At times like this, the only person who could calm her and bring her peace was my mother; however, at this point *Nenek* thought she was her older sister.

Although *Nenek* had entered a very confusing world, we all wanted to see her smile again. It was obvious she was now living in the past, so when I remembered seeing photos of *Nenek* as a young woman, standing beside rows of colourful flowers at a market, I suggested my mother take her flower shopping. That’s exactly what happened. We packed her wheelchair in the back of the car and took her to the flower market. When we arrived, her smile was radiant, and we knew she was having the time of her life. We ended up buying almost all the flowers we could get our hands on and eventually, we set up a small flower garden for her at home.

On days when even the brightest flowers failed to calm her, we had to be more creative in bringing her back to her younger, happier days. For example, we would play P. Ramlee movies or songs on the television. Miraculously, she would recite the lines to the movies and sing along to the songs without missing a beat!

Whilst everyone was trying their best to care for *Nenek* and keep her happy and comfortable, I knew that my mother was trying to hold things together. Having to switch from the corporate life to staying at home and caring for both her aged parents, when she had been battling her own medical issues, had taken a toll on her wellbeing. *Atok*’s health had also progressively deteriorated and eventually he left us peacefully in 2020.

With *Atok* gone, *Nenek* felt even more adrift, confused and uneasy. We could tell she was constantly searching for comfort; the comfort she had found in *Atok*. She didn’t understand the loss and would ask for her father, but we understood that really, she was just looking for *Atok*.

Many financial sacrifices had to be made to ensure *Nenek* was comfortable, especially when she became bed bound and refused to eat solid foods. COVID-19 had also hit the nation. With *Nenek* being so vulnerable, the rest of us had to be extra vigilant about our choices and our movements.

Not long after this, *Nenek* was being fed through a tube and did not speak very much. Although she only recognised my mother, she continued to give the rest of us her warmest smiles. Some days, she would sleep continuously for 48 hours, then stay awake for the following 48. We knew that her time would soon be up, and we did our best to make sure she was comfortable and was never alone. 2022 rolled by, and after 2 years of being apart from the love of her life, she finally joined *Atok* on the fifth day of January. She was 83.

Dementia doesn’t change a person. It brings them back to their core memory and we help them by finding out how they choose to be understood and loved.

Nenek, if you could hear us today, know that we had our absolute best times with you and we will forever cherish your love. ■

BRUNEI DARUSSALAM

He is still my father: a deeply personal story

Mr Chew Tong Zong (88) was diagnosed in early 2021. His son and carer, FC Hing, wrote this moving letter.

Dear eBook Project,

Allow me to introduce myself. I am FC Hing. I have attached a photo which I believe captures the essence of my father and our family. We have chosen to share a deeply personal story: the journey of caring for a father with dementia. We do so in the hope of helping others in a similar situation, shining a light on the profound impact this affliction has on both individuals and families. Given the weight of daily challenges and the emotional toll of my father's diagnosis, I also want to raise awareness of the multi-faceted fallout from this disease.

My first-hand experience has given me an unyielding appreciation of the physical, emotional, and mental toll this journey can take, and the critical importance of and need for compassionate care.

I am eager to continue raising awareness and advocating for those impacted by this debilitating condition. I firmly believe that together we can cultivate a deeper understanding of, and offer unwavering support for, those affected by dementia.

My father

Throughout his life, my father was an indestructible force – a pillar of strength that our family always relied on. With unrelenting dedication, he worked tirelessly to provide for us, always placing the needs of others before his own. However, as he entered his late 80s, we observed subtle changes in his behaviour. He struggled to articulate his ideas and his once sharp memory began to falter. Soon enough, the devastating diagnosis of dementia robbed him of his vitality. We were left with the arduous task of making challenging decisions: ones we had never before encountered. Coping with the heartbreaking decline of a loved one, while attempting to preserve their dignity, is an incredibly daunting journey. It tested our strength and our resilience, yet we have learnt to cherish every moment we have left with him. We celebrate the man he was, rather than focusing on the dementia that is slowly taking him from us. The following describes the emotional impact this disease has had on our family, and the daily struggles we face in caring for him. I will also share my own experiences and emotions as we navigate this difficult journey.

My family as a whole

Firstly, as a family, we are aware that dementia is a progressive illness: one that can significantly affect an individual's cognitive ability. This includes memory, decision-making processes, and communication. Our father is experiencing these symptoms, and it has been challenging to witness his decline. As a family, we have had to make some difficult decisions, such as arranging for his care and managing his finances. This has added to the stress and pressure of an already fraught situation. Furthermore, the emotional toll of caring for someone with dementia is substantial, and it has impacted us all. It can be overwhelming to see our father struggle with everyday tasks and become increasingly dependent on others. The fear of losing him, both physically and mentally, is something that we carry with us daily. As a result, we have experienced a range of emotions: from sadness and anxiety to frustration and anger.

On a psychological level, the impact of our father's dementia has been profound. It has disrupted the family dynamic and forced us to reassess our roles and responsibilities. We have had to adjust our expectations and goals. When dealing with a loved one's illness, this can be very difficult. It has also raised tough conversations about end-of-life care and how we want to support each other during this challenging time. Nevertheless, we remain hopeful that with time and proper care, we can help our father manage his illness and maintain his quality of life as best as possible.

For me, as an individual

Caring for a person with dementia has taken a toll on me physically and mentally. I constantly feel exhausted and drained, and it is becoming increasingly hard to balance my own daily activities with caring for my father's needs. While the physical demands of caring for him are taking a toll on my body (causing fatigue, back pain and muscle strain), it is

With unrelenting dedication, he worked tirelessly to provide for us, always placing the needs of others before his own.

the emotional burden that weighs heaviest on me. It is heartbreaking to see my father's mental abilities decline, and it is overwhelming to know that I am responsible for his care and wellbeing.

Despite these many challenges, there are times of joy and connection. At times, my father's love for singing and poetry has allowed us to share beautiful moments together. Recently, I was able to piece together the meaning of one of his poems, and it moved me deeply. In it he expressed his love for me and his hopes for my future, reminding me that even though he is suffering from dementia, he is still my father, and his love for me remains.

Amidst the heart-wrenching reality of my father's dementia, I am acutely aware of the immense challenges that my family faces. The profound sorrow of watching a loved one's faculties decline is compounded by the overwhelming demands of caregiving. I have borne witness to the frustration and emotional withdrawal that can ensue, but I do not fault my family members for this. As a devoted son, I am unwavering in my commitment to providing my father with the exceptional care that he deserves. I will tirelessly support my family through this tumultuous journey, drawing upon a reservoir of love and compassion to navigate the difficult road ahead. For us, no obstacle is too great, as we stand together, united in our steadfast devotion to my father's wellbeing.

In conclusion, I wanted to share my story with all of you because I believe it is important that we come together and offer support to one another during such times. Caring for our father with dementia has not been easy. However, by working together, we can navigate a way through the many difficulties and ensure that he receives the care and love that he deserves. ■

Sincerely,
FC Hing

HONG KONG

Anxious about my future

Ms Sau Ying Wong (63) was diagnosed with dementia in 2020.

In the past, I told my son: *“Being willing to take care of others will make your life more complete.”* But when he actually needed to take care of me, the reality was not as I had imagined, especially as this day came too soon. Shortly after retirement, my memory started to decline. Once I even left my house without turning off the stove. When these unusual events continued to happen, my husband and I both sensed something was wrong. Following medical check-ups and assessments, I was officially diagnosed with dementia. At that time, I didn’t know anything about this disease, so I immediately did an online search. The more I read, the more worried I became.

Before I retired, I worked as a senior manager for a company. I was competent and took pride in the accuracy of my analysis. Now, I cannot even work out 28 plus 34. Faced with this increasingly incompetent self, I have nothing but

anxiety about my future. This disease not only affects my cognitive function; it also affects my balance. Now, because I am afraid of getting lost and falling, I dare not go out alone. If I want to go to an old school reunion, before I decide to attend I'll see if someone can pick me up and drive me home.

> I hope that, while I am still capable of doing something, I can continue to use my strengths to handle things for myself.

Last year, my husband suddenly passed away. The person I thought I could rely on was gone. Why did he leave me so alone? I cried every day and I wanted to die. I thought if I joined him, I had no need to worry anymore about the future. However, siblings, friends and staff from the Hong Kong Alzheimer's Disease Association were encouraging and accompanied me through those dark days.

My brother has now moved into my home, and he has become my key carer. Sometimes I argue with him. Maybe he has good intentions, but I hate being treated like a child. It seems that I am unable to do anything without permission. Even when I am having a meal, I am asked to chew ten times before swallowing, to avoid choking. I hope people around me understand that I still have my dignity and I would like to be treated with respect by others. I hope that, while I am still capable of doing something, I can continue to use my strengths to handle things by myself. There is no need for others to do everything for me.

My son will return from the UK in a few months. He recently obtained a master's degree from a prestigious university and secured a satisfying job. Because of my illness, he changed his plans and will come back to Hong Kong. This makes me feel guilty. As a mother, I was supposed to take care of everything for him so he could go and live his own life. Now he is sacrificing an established career to devote himself to this unknown role of carer. He probably also bears a heavy financial burden, due to my ongoing medical expenses. Both he and I are afraid of regretting this decision. Will my brother or my son get tired of taking care of me and leave me one day? I am worried about this possibility.

At the moment, I'm still in the early stages of this disease. At the day centre, I see friends more seriously afflicted with dementia than I am. They seem disconnected from the world. When my cognitive ability deteriorates further, I may have to live in a home for the elderly. I am very anxious and worried about whether or not I could adapt to new people and a new environment on my own. I know that one day I will be hollowed out by the disease, forgetting people and memories I cherish the most. I will forget their kindness to me and their love for me. I am so sad. ■

INDIA

Caregiving.
It wasn’t a lost cause.

Madam Raj Rani Madhan (78), diagnosed in 1997/98 is cared for by her husband who is her primary carer. Their journey is narrated by their daughter, Bina Berry.

Alzheimer’s was a distant word in my vocabulary by the time we knew my mother had it. There was little if any awareness of dementia and Alzheimer’s in the early 90’s in India. It was accepted that as our elders aged, they would become forgetful; do things out of the ordinary; be confined to their beds; need some level of caregiving. That the young will look after their old is still very much a given in Asian societies.

My parents lived alone when my mother was diagnosed with Alzheimer’s. Fortunately, I stayed close-by with my two children. In the initial stages, my father was my mother’s primary carer, while I was busy running my business and my home. However, since I met my parents every day, I could see the changes that were taking place. We were bewildered and confused when we saw my mother transforming from being a social, amicable person into a recluse, who was becoming silent and careless about her own grooming. She had even given up her greatest passion: cooking and feeding delicacies to her loved ones.

For a long time, whenever she visited the doctor, she was diagnosed with depression and was administered anti-depressants and sleeping pills. I suspect this only made the situation worse. Even when she was diagnosed correctly, we went into denial. How could a vibrant, well-cultured and well-travelled person, especially my mother, possibly have Alzheimer's?

I came out of the denial stage quicker than my father and we set about trying to do things for her together. By this time, we had begun to research and understood the illness for what it was. Sadly, none of the medical practitioners advised caregiving as a powerful tool, even though in the absence of any medication, it was the only tool available to us. Caregiving, as we undertook it for my mother, came to us naturally and according to our sensitivities, so we were able to change our techniques according to her acceptance or non-acceptance of whatever we did.

Mom's condition persisted for nearly ten years. During this time, she had a number of strokes, each one having a deteriorating impact on her condition than the one before. About three years before her death, dad could no longer look after her, due to his own old-age problems, and I realised that I would have to decide by myself how we lived with my mother's condition.

With each passing day, I paid less and less attention to my business, resulting in a loss of clients. Finally, in desperation, I contacted an agency to ask for an eight-hour shift carer.

Since there was no concept of a specialised nurse familiar with Alzheimer's, I would have to make do with a housemaid who could provide those eight hours. My mother rejected each and every one of those helpers. She only wanted me close to her. I was lucky because my children offered to help, providing company and doing odd jobs around the house.

At this point in the story, you may think this is all a lost cause, but I would not agree. Mom's illness brought me closer to both my parents. With my three siblings settled in foreign countries, I was the only one close to them now. Dad shared a lot with me and in the initial stages, as did mom.

As her illness progressed, my mother still surprised me with her recollection of past events. She even shared with me stories of her love life, marriage to dad and bonds with friends who had lasted a lifetime. I would say that was the biggest gift she left me. Her memories, sad and happy, were being downloaded to me.

I had not looked at caregiving as a scientific discipline. I just followed my instincts. And, since caregiving was not a discipline, neither was time-out for the carer. My time-out happened after mom's death, then my dad's death a week later. Shattered, I closed my business, which was already making losses, and began to rebuild our lives. In the following year, I thought a lot about mom and her illness. I joined a social organisation linked to Alzheimer's and caregiving and learned more about both. My constant thinking of mom resulted in a memoir about her. This is one of the first in India addressing the subject of caregiving for people with dementia. The catharsis had happened, and religion and spirituality played a great part in it.

There are many more services in place now than when my mother had Alzheimer's. There is also a greater understanding of the disease. Furthermore, the walls of denial have begun to fall away. Families recognise the benefits of hiring professional carers and luckily, there are now specialised nursing staff capable of doing this job. Given the new nuclear family set-ups, one of the greatest demands of our time is for special homes for people with Alzheimer's: for both day and full-time care. While a number of these homes have begun to spring up, there are not nearly enough of them.

In order to create a society which is inclusive for persons with dementia and Alzheimer's, the government will have to pay more attention. Small steps have been taken, but these are not enough. A plethora of old-age homes exist under government initiatives, but there is nothing noteworthy or specific to Alzheimer's. Here, I refer only to the urban context. The huge gap that exists between rural and urban conditions is both shocking and unacceptable.

The handful of doctors, volunteers and journalists who are giving their time selflessly to this cause can only do so much. I hope more and more people will donate whatever they can to make the lives of our elderly easier. After all, this is the land where seniority and the wisdom of elders is revered, isn't it? ■

INDONESIA

Living with dementia – is not the end of the world

Bapak William Buntoro (74) was diagnosed in early 2018.

Hi everyone! My name is Bapak William Buntoro, or as I'm fondly known, Pak William. I am from Jakarta, Indonesia. I am 74 years old and I have a wife, three children and two grandchildren who are always there and loyal to me. Entering an age that can be described as having "passed half a century" is an immeasurable blessing given by God Almighty. God is great. He's really great!

Treading the twists and turns and the ups and downs of the wheel of life, my journey to reach this age has not been a particularly smooth one. It's like being on a rollercoaster, with so many unexpected "surprises", but in the end I am very grateful.

One such blessing occurred in early 2018, when a neurologist diagnosed me with Alzheimer's Disease. Initially, my family and I were quite shocked. However, after the neurologist explained risk factors, various solutions and the best treatment therapy, I was determined not to sink into despair. I didn't want to mourn or look back. Rather, I decided to try and remain positive: to keep looking forward and live my new life as someone now living with dementia. The support from my immediate family, close friends and relatives who knew about my condition has been very, very meaningful. Furthermore, I can personally tell you that being an *Orang Dengan Demensia* or *ODD* (person with dementia in *Bahasa Indonesia* language) is not the end of everything.

Following my diagnosis, as an *ODD*, what were the next steps I should take? From a range of sources, my family tried to collect as much information as possible about Alzheimer's Disease. Thanks to social media, my children eventually discovered and asked me to join Alzheimer Indonesia (ALZI). ALZI is an organization for people diagnosed with Alzheimer's and other dementias. It has several regional chapters located throughout the country. ALZI is also a member of Alzheimer's Disease International (ADI) based in London, United Kingdom. Without thinking about it too much, I said 'yes' to the invitation. After this, I found a lot of new friends: from administrators, assistants, nurses, experts and doctors to the *ODD* themselves. It turns out I'm not alone. Getting to know all these people is like having a new family. Importantly, my family and I can access information, knowledge and find solutions to problems in a very comfortable way. Along with regular consultations with the doctor who treats my disease, the encouragement, support and warm hugs from Alzheimer's Indonesia are exactly what I need. Thank you so much ALZI!

And my message?

Stay active and think positively about living an *ODD* life.
Alzheimer's Disease cannot be cured. There is no drug available for many disorders of the brain, including the one I have and is experiencing. However, this doesn't stop me from living. Again, God has given me this "blessing", and I have to have faith that there are many good reasons for this happening, even if I don't know what they are. Do I lament the situation? Certainly not. In fact, accompanied by a family carer, I try to conduct my daily activities as normally as possible. That is my main goal right now.

Filling in free time by taking up hobbies and positive activities is something to be encouraged. For example, I try to improve my brain's performance by staying socially engaged. Having good relations with old friends, relatives and those who understand my condition definitely helps. Also, I participate as much as possible in the various activities organized by ALZI. I feel really comfortable doing this, and of course I do so with the assistance of a family carer who is constantly at my side.

Being *ODD* doesn't prevent me from engaging in my hobbies or expressing my passions. Whether it's taking care of plants and pets at home, visiting shopping centers, sightseeing around the mall, travelling out of town or even abroad, it's all relaxing, right? Of course, as my beloved wife, children or grandchildren are always beside me they automatically become the most loyal of all family carers. Therefore, maintaining good relationships with them is essential, as is following recommendations of the doctors and medical personnel who really understand dementia.

Let's break the stigma!
It's not an easy thing to look after an *ODD* like me, especially for a 24/7 family carer. You don't need to wonder what an *ODD* does most. Asking – over and over again, every day – is the answer. It doesn't matter if it's someone's name, events, or small details relating to the day, purpose, directions to/from somewhere, or something I just did. Not infrequently, time disorientation also occurs. This too is a symptom of *ODD*. Not being able to find something I am looking for has become my daily struggle. Don't ask where I put it or have stored it! There are times when seemingly trivial things become huge. This has an impact on my emotions, and can affect my family carer, making them agitated too.

Give up on the situation? Never! Don't despair. Surrender to God and pray for strength, which is what I have done. Thanks to close relationships (including mutual understanding, love and affection from a family carer) I have become a strong person living with dementia. Even now, I stand tall and proud. If ordinary people were to judge me from my appearance, they would never guess I have Alzheimer's Disease.

Being *ODD* is not a disgrace and it is nothing to be ashamed about. Don't ever equate *ODD* with mental illness! These are two very different diseases. *ODD* behaviour is different from that exhibited by persons with mental disorders. It's time to get rid of the stigma that links the two and leads to misunderstanding and discrimination. Together with fellow *ODD*s around the world, I speak out against this issue. It's time for people to open both their minds and their eyes and understand that an *ODD* is able to lead a normal life. Let's get rid of confusion and stigma attached to *ODD* forever. ■

JAPAN

You have early-onset dementia!

Miki Sato (48) was diagnosed with dementia at 43.

Diagnosis and beyond

I was 43 years old and living with my husband and high-school-aged son when I received the diagnosis of “early-onset dementia.” Looking back on those days, I realized I knew nothing about the disease or the discrimination against people who suffered from it. The internet provided only negative information, suggesting that in a few years, I would be bedridden. The diagnosis immediately overwhelmed me, and I felt “dementia” meant “the end of my life.” In the examination room, I repeatedly apologized to my husband, who was sitting next to me. *“Sorry, sorry,”* were the only words I could manage amidst my tears.

Why did I apologise? Our son was diagnosed as being on the Autism spectrum, and we had had a tough time parenting him. I experienced physical and mental health problems during that period and was repeatedly hospitalised. As my son became a high school student and grew up, my health gradually improved. This was supposed to be a time when we could look forward to our son's future with hope, but now, because of my dementia, I would be a burden to my husband in his prime and my adolescent son.

My husband silently caressed my knees. I understood his message of love, *"Don't worry, I'm here."* I spent more than six months of my life shut up at home in deep sadness and despair. I was unable to care for my son, who was maturing so well, and I did not want to expose my family to my rapidly declining condition. I wanted to disappear before I became a burden to them. That was all I could think about.

A turning point

"I can't keep doing this." There were so many days when I was simply overwhelmed by this thought, but eventually I felt that I would like to meet people diagnosed with dementia and see how they were living their lives. One day, I encountered Mr Tomofumi Tanno, an active dementia advocate. I tagged his name on my Facebook page, added a self-introduction, and posted my comments. Through this, I met Mr Takua Morioya, manager of the daycare centre where I now work. Mr Morioya was concerned about me being confined to my home. Although he invited me to his daycare centre for rehabilitation, I could not bring myself to visit the facility. Nevertheless, he continued to send me thoughtful messages, and enquire about me. Finally, I was able to get myself motivated and I visited the daycare centre.

Mr Moriya's daycare centre

Unlike the day-service facility I had imagined, this was a house in an established residential area, where clients enter with a smile

and a cheerful *"I'm home"*, just as if they were home. Later, this daycare centre became a special place: one that inspired me to become more active. After I became accustomed to the centre and could enjoy myself there, Mr Moriya suggested I become a staff member. I could not believe this, and I asked him if it was really possible for a person living with dementia to work. Mr Moriya replied, *"Regardless of whether you have dementia or a disability, here both staff and users are members, and we have an equal relationship."* This was a big turning point in my life.

The second chapter of my life

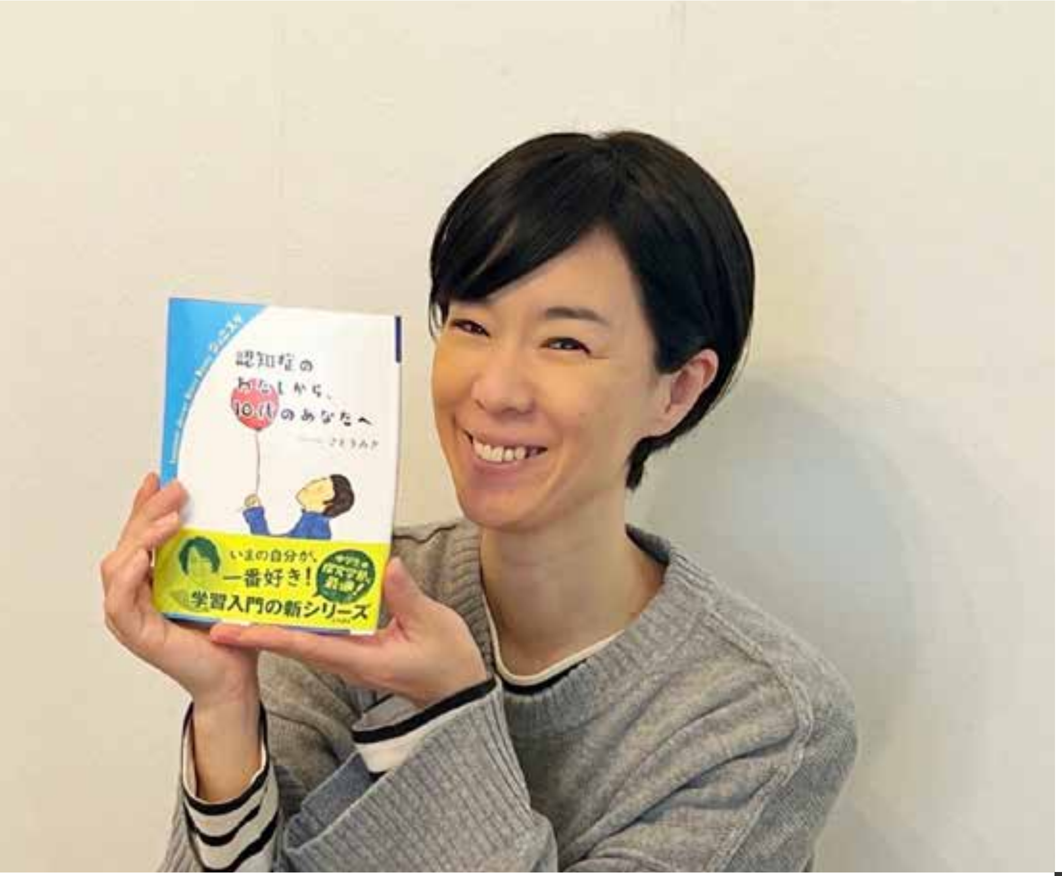
I am not who I used to be. I was diagnosed with dementia, but since then I have been given a number of new opportunities. I now work as a staff member at a daycare service, where I myself provide peer support for others. I lecture and write, and I engage in numerous other activities, including as an airport universal-design team member. Furthermore, I re-started my spokesperson work for a company where the manager understands and accepts my condition (namely, that I live with dementia.) Through my many activities, I want society to understand the diversity of, and possibilities for, people living with dementia.

I feel that now is a most fulfilling and enjoyable time in my life. Of course, sometimes I experience much inner turmoil and hardship, and the anxiety brings me to tears. However, the following precious expressions give me courage: *"Live in the present," "Be myself,"* and *"Respect myself."*

Those living with dementia just got it a bit sooner than others. A diagnosis of dementia does not change us in any way. What changes, as a result of prejudice and discrimination, is the way people look at us. When a person with dementia can no longer speak properly, many people automatically think they don’t understand, or they can’t do anything. However, I have learned through my own symptoms and through my experiences at the daycare centre that people living with dementia still have words they want to say in their heads. When I have been unable to express my feelings or thoughts to my family, I have been frustrated and tearfully shout, *“I have no idea. Yes, I am stupid.”* Likewise, others may not always be able to speak as they want to or be able to express themselves appropriately. When I spend time with friends who have dementia, I can help those having difficulty with speech. Being close to them enables me to support them by looking for “hints” of their words, and little by little they can sometimes find and piece those words together, their faces beaming with smiles when they do so.

Those of us living with dementia are aware that our sense of time is different from others. This makes us feel uneasy, but even so, we desperately try to do our best. We have a lot of things we want to do for ourselves, and even if it takes longer, we are still happy with our sense of accomplishment when we manage it. If people understand our condition, when they support us with empathy and without rushing us, we can try to accomplish more, no matter if it is a little “dream” or just a small wish. We can take a step forward if someone accompanies us.

I want to tell you from my experience that the dementia journey can be delightful and fruitful. We, the people living with dementia, have no time to wait or to waste. Postponing support and legislation will never provide us with hope. It is a fact that anyone can get dementia. If we own this, rather than thinking of it as someone else’s problem, the world would be better place: not only for people living with dementia, but also for people living with other diseases and disabilities.



I am not who I used to be. I was diagnosed with dementia, but since then I have been given a number of new opportunities.

People living in harmony with each other makes life better for everyone. Having dementia does not mean the end of life. We, the people living with dementia, do have a future, although we may be *“just one step ahead of others in our dementia journey.”* ■

JAPAN

Coming back to life!

A mother of three sons, Shinobu Yamanaka (45) received her diagnosis of dementia in February 2019.

I live in Kochi prefecture, in the western part of Japan. I was diagnosed with early-onset dementia when I was 41 years old.

Diagnosis and afterwards

Since 2017, I had felt something was wrong with me. Before the diagnosis, I had experienced troubles, both with my family and at work. One day, my eldest son was watching a story about dementia on tv. He thought I had the same symptoms, so he asked me to consult a specialist. Following a range of tests, I was diagnosed with early-onset dementia in February 2019. My mother said she was sorry for giving me this disease; that she wished it had happened to her instead, but I replied: *"It is better I have it. To be forgotten is more painful than to forget."* In any case, I was somewhat relieved to know the cause of the problem and I appreciated my doctor's heartfelt encouragement when he gave me his diagnosis. My second-eldest son also encouraged me, sending me the following message: *"Don't yield to the disease."* However, I fell into despair when the only information I could find online about dementia was useless and negative: a ten-year life expectancy… loss of intellect… institutionalisation and so on. How could I ever forget my sons? Does having dementia mean I would be sent to an institution? Because of these rising fears, my depression got worse and worse, and I kept to my bed. What could I do to raise my kids as a single mother? How could I pay for their school fees? When my son said he had given up university, I felt guilty and miserable. Crying at midnight, staring at my life insurance card, I thought of suicide. Though the people surrounding me at the time were kind, I was not yet ready to consult with them about this hardship. I shut my mind.

Coming back to life

Despite the amount of hopeless information on the internet, there were some positives. I found Mr Tomofumi Tanno. He was living with dementia and enthusiastically providing others with peer support. In reply to my Facebook message, he sent me a book. Without it, I would not be able to smile or live such a positive life. In fact, just thinking of him makes me smile and strengthens my resolve to continue living this way. Having become positive about the future, in 2021 I visited DAYS BLG in Hachioji city, a suburb of Tokyo. This daycare centre is jointly managed by a corporation of staff and people living with dementia and the focus was on creating work opportunities. I joined the activities and was impressed by the equal relationship between the service users and service providers. Highly motivated members of DAYS BLG actively participate in the community in a very positive way. This inspired me to start a similar movement in my hometown of Kochi.

Opening the HAPPY Daycare Centre

I decided to establish a daycare centre in order to make my town a Dementia-Friendly Community. However, there were many challenges in starting it, unsurprisingly because I myself am a person living with dementia. I explained the vision and mission of the proposed daycare centre to many people and asked experts, such as legal professionals, for their help and collaboration. Finally, in 2022, the new daycare centre was opened. I named it HAPPY, hoping that it would be a place where no one felt alone. I am grateful to all of you who shared my thoughts and worked hard with me to make this possible. HAPPY differs from other daycare centres, where users only receive services. In the first instance, we refer to people who join HAPPY as "members" not "service users". We also have contracts with local industries, such as farms, automobile dealers, building custodial companies, etc. We get paid for our work and we pass this on to our members as salary. After all, work and social inclusion are basic human rights. An essential role of HAPPY is to make members' wishes come true. For example, when one member was able to buy a Christmas present for his wife and able to write her a *"Thank you"* message, his wish had come true. Furthermore, his wife was deeply moved when she received this gift and saw her husband's words to her.

I decided to establish “HAPPY” Daycare Centre in order to make my town a Dementia-Friendly Community.

Establishing a friendly community for everyone

Since I started HAPPY, I began to understand the feelings of people willing to help others like me who need support. As a person living with dementia, I often said that I was embarrassed when I am asked by someone how they could help, or what support I require. I am sorry about that because there are days when, at HAPPY I myself ask someone with dementia these very same questions, because I want to get to know them. I also realise that people were asking me lots of questions back then because they were trying to support me. In other words, I understand both the feelings of people needing help and the people willing to support them. I want to build a friendly community for everyone by valuing people’s feelings on both sides. Of course, the members and I face challenges day upon day. However, our activities give us energy and hope. I believe we can continue to make this happen by collaborating with our members and other people who share our values. Furthermore, I am sure that the activities at HAPPY will lead to people feeling comfortable enough to ask for “Help” when they need it.

A message to people living with dementia and all others

Many people living with dementia might think they have to give up their wishes because of the disease. However, many possibilities remain if they collaborate with people who can share in their vision. I learnt this from my own experience, opening and running HAPPY. Our story continues and it involves all the people in my community, regardless of whether they are living with or without dementia. Let’s remain positive and write a heart-warming story of living well with dementia – together. I stand for you and with you! ■

JAPAN

Early-onset dementia – diagnosis and coordinators' support

Masanori Watanabe (46) was diagnosed with Alzheimer's disease at 40.

I was born in 1977 and diagnosed with dementia when I was 40. I could not believe the diagnosis because I thought dementia was an older person's disease.

However, I also felt some relief at this news. I had sensed something was wrong and had been anxious about causing trouble at work. After the diagnosis and getting some information about Alzheimer's Association Japan (AAJ), Saitama prefecture branch, I went to see an early onset dementia coordinator about my situation. The coordinator helped me understand my diagnosis and explain the situation to my family and my workplace. In addition, I was given assistance with the leave of absence process. I don't think I would be where I am today if I hadn't met with the coordinators at the centre.

Dark days

While on leave of absence, I lost all motivation. I didn't think I could start anything new now that I have dementia. For days on end, I did nothing but play games on my smartphone, isolating myself from society. In the end, I also resigned from my job. Although the coordinators invited me to meetings, I declined their offers and stayed away.

Inspired by intercommunication with people living with dementia

One day, I experienced a change of mood and attended a lecture. There I met with and listened to two people who were both living comfortably with early onset dementia, namely Mr Tomofumi Tanno and Mr Masahko Sato. I was also quite grateful to have met Mr Masahko Sato, who inspired me because he was trying his best to succeed in a number of different areas, including finding a job.

Expanding activities

By interacting with people living with dementia, I became more positive myself. I started working as the manager at *Rin Cafe*, a place supported by the AAJ Saitama prefecture branch, where people with early-onset dementia and their families come together and connect with one another. I named the café *Rin Cafe* because it means "reincarnation", or starting life over.

When people share the same space at *Rin Cafe*, even if they only spend a little time there, change becomes possible. There are many things to talk about because we have all been through the same experiences. In September 2021, I was appointed *"Saitama Prefecture Orange Ambassador"* and am responsible for promoting public awareness of dementia.

Re-employment

Next, I began to think about finding a new job, as I had learned about the "labor transition support" system. I repeatedly applied for this, but in two years, not a single company was interested in, or approved my application. I think this was because the word "dementia" was on the form. When I consulted with my coordinator, he advised me to apply to a company that would interview me, instead of screening my application.

Eventually I had an interview with *Persol Thanks* - a corporation that supports people with a disability (https://www.persol-group.co.jp/en/). The company recruited me, and I have since regained the joy that comes from working. *Persol Thanks* later changed its name to *Persol Diverse* on 1 April 2023.

My work and mission

My current job description is to assist those who come for practical training from support schools and labor transition support offices. Although I had a very difficult time finding a job myself, I am now able to use that experience to help others. When I look at the employment records of companies that hire people with disabilities, very few employ people living with dementia. It is sad and frustrating. However, I think something might change if I'm able to show people I can work and that I am happy.

At my present workplace, I am provided with a lot of support. But, in order to prevent mistakes, I also take care to share information, etc with those around me. If there is a problem, I immediately inform everyone during a meeting. At work, I receive many *"thank you's"* and smiles from the trainees. I am very happy that I am able to continue working while sharing smiles with them.

I feel that I need to be prepared for the fact that my symptoms may eventually progress, and that, in the future I may face many difficulties. However, I hope my sharing and working experience at *Persol Diverse* will inspire others.

A message to my colleagues – today and tomorrow

Believe in your potential. Work and laugh together. ■

MACAU

When I discovered my mother has dementia

Mrs NI Lou (68) was diagnosed at 67. Her story is shared by her son and carer, Danny Leong.

My mother is a housewife. From the time I was born, she has taken care of me and my younger brother. We have always felt that she was very adaptable, and that her life was very interesting. She has been involved in various foreign exchange and stock markets. She has also researched, developed and written many recipes. Regardless of anything else, she has always made time for us. Unexpectedly, while she was still young, she was diagnosed with dementia.

About three or four years ago, I realized that she had become quite forgetful. The most notable time was when she forgot my birthday. On that day, there was no *"red envelope"* (a traditional Chinese blessing of monetary gift). On my birthday, first thing in the morning, I had always received this gift, so I was very disappointed.

However, I thought that she had simply forgotten because she had been spending a lot of time and energy on her newborn grandson. I felt a little concerned and helpless, but then I reassured myself, saying, *"I am already in my 30's. Should I still expect a red envelope?"* Of course I expected it. But right now, my only wish is for a healthy mother, though it's a wish that cannot be fulfilled.

Apart from significant dates, our mother has gradually forgotten other things too. The most dramatic incidents involved the family and occurred when she forgot to turn off the stove, about three times in the same year. At this stage, everyone realized the situation was serious!

I remember seeing her on the street two years earlier. She was ready to go home but confused about which direction to take. This image was deeply imprinted on my mind. Will her condition improve? Occasionally I still think so.

After more than a year, with various approaches and input from many relatives, friends, and indeed the whole family, she finally went to the hospital and underwent some tests. As expected, she was diagnosed with dementia. Since I knew that this disease was irreversible, in the early stages of my mother's diagnosis, I took some courses offered by the Macao Government, and in the library, read books relating to the disease. I learnt that consulting a doctor and taking medicine could only delay her decline and that the impact of dementia would soon be reflected in her everyday life. We had always relied on her to take care of the whole family's needs, but with this situation being reversed, each family member would have to change their role and personal responsibilities in order to adapt.

At present, although our mother seldom walks in the street, in her mind she goes to the park for exercise in the mornings and evenings. She also shops at the market in her free time and has trips with her friends. She says these same things to us every day, so maybe they reflect her favorite way of life!

With regards to family life, my mother's ability to look after herself in this context is fine. Furthermore, because she lives with her family, everyone helps takes care of her. But away from home, all kinds of situations and difficulties are possible. So, gradually, family members have made various adjustments in order to deal with this.

Personally speaking, the change of roles, from care receiver to carer, means we interact differently. In the beginning, I did not know how to get along with her. I was irritable, I was angry with her, and occasionally I sulked. Then, I slowly learnt to be more tolerant, patient, and understanding. This is a very special process, and I suddenly found myself growing up. One evening, my mother and I were chatting. I was talking to her about something when she said, *"Just speak to me slowly. I will understand."* At that moment, I recalled her love for us over the years. Although this word "love" has never been said out loud, she expressed it through decades of actions. She taught us systematically, and with great patience. She was meticulous and she was diligent. Now it is my time to contribute. In the days to come, I will do my best to take good care of and cherish this "young friend" – my mother! ■

MALAYSIA

It’s a long journey. Let there be laughter.

Jenny Lim shares positivity in caring for her mother living with dementia, Madam Tan Giak Moh (91).

Madam Tan Gaik Moh was born in Songkla, Thailand. She was adopted by a childless couple in Penang. During her early teen years, she started working to support her family. She married at the early age of 17. She began sewing to earn a living and later she ran a factory manufacturing clothes. She has three daughters and one son. Her eldest daughter lives in Dallas, Texas. Her second daughter is in Butterworth, Penang. Her youngest daughter and her son both live in Kuala Lumpur. Her hobbies include watching movies, sewing, and playing cards. Fashion designing was her passion, but recalling the steps are a challenge these days.

Madam Tan’s forgetfulness started about 10 years ago. We noticed she kept stitching the clothes incorrectly, then she started to lose interest in sewing altogether. She began sleeping more during the day, but sometimes she would wake up at 1.00 am to take a shower. Gradually she also gave up cooking. She started to ask us how to do this or that because she had forgotten. She also forgot how to write words that she knew, so she would draw pictures to represent the words.

Because our family unit has different generations living together, our Mother's care has been relatively easy to manage. We would say that involving her in family life and giving her responsibility for tasks entrusted to her helps her self-esteem. She continues to assist by doing whatever she is still able to do.

There are good days when she remembers things; when she is more alert and engaged. Then there are times when she sleeps more during the day and wakes up at night, asking if it is already daylight. She will keep saying that she is not hungry, but with encouragement, she will eat. She forgets what has happened and sometimes says she wants to go out to work and be financially independent. Nonetheless, together we share many good memories.

We have noticed that engaging my mum in tasks to fill the time has definitely helped in slowing down the progression of dementia. Sometimes we need to re-teach her how to do things she used to do. Then she remembers, but in just a couple of days, she will forget again. Although it is a long journey, living in unity and letting her forgetfulness generate laughter, rather than anger, will soothe and calm the situation.

We understand that engaging a full-time carer may not be the answer; the burden on one person simply being too great. Furthermore, a single carer may not have the capacity to provide the 24/7 care that would be available in a nursing home. In other words, we know that there will come a day when we may have to rely on long-term care in a home for our mother. Our wish is to see the realization of the National Dementia Policy, so that important regulations will be passed and benefit persons living with dementia and their carers. To further enhance the Standards of Care and Quality of Life for Persons with Dementia, much planning is still required. This should be based on: culture, infrastructure, religious perspective, economy, etc.

The list goes on, but let us take one baby step at a time and do what we can. ■

Thoughts from Madam Tan Giak Moh...

I am Tan Giak Moh, and I am 91 years old. I have many grandchildren and great grandchildren. I am currently living with one of my granddaughters. Every day I keep myself busy with the little things that I am still able to do. Previously, I owned a manufacturing clothing business where I designed, made samples and later mass produced the clothes. My daughter says I have to 'work' to keep my memory intact. My daughter and granddaughter do the laundry every day. My job is to fold the clothes and also to iron those that require ironing. I have cataracts in my eyes. I am on medication for hypertension and sometimes I have gastric problems.

Sometimes I cannot remember things, and I do not know what I need to do. Most days I hear voices… a man's voice singing in the distance, in the Teowchew dialect (my original language). I also see people passing by me. When I try to see who that person is, it is very strange – they are just not there.

My daughter asks me to exercise and socialize, to keep myself active and healthy. I am still able to climb the stairway to my room. My other 3 children and relatives call me on the mobile phone. They keep me updated on what is happening around us. Most nights I will dream that I am walking on a very long, uphill journey, with no one in sight. Initially, I was scared. Now I have gotten used to it. I do not understand why. It is very strange.

My great grandson keeps me company after school. He tells stories about his friends. He wants to learn Mandarin and I speak with him in this language. In turn, he will talk to me in English (but I do not understand). He cannot speak Hokkien very well, but he is a good boy.

Time passes quickly with many things to do each day, and I am happy.

My granddaughter likes to take me out, but most times I do not like going, because of the COVID-19. Also, my legs are not steady, and I do not like the inconvenience of going to the washroom when we are out.

Thank you for listening to my story.

MALAYSIA

A complexity of emotions

Kanchana Davey, a carer to Madam Letchimy (78) shares her multiple 'roles' as *'older sister'* as well as daughter.

My name is Kanchana Davey. I am my mother's carer. Mom thinks I am her 'older sister', but every now and then she remembers me as her daughter, though this only lasts for brief periods.

Four years ago, mom was showing symptoms of dementia. Quite unexpectedly, we all became her carers. This was a new experience for us. Caregiving for a person with dementia was (and is) totally different from everything else. It is both confusing and frustrating. Furthermore, as carers, we have no outlet for expressing our own concerns or emotions. Although caregiving plays an essential role in the lives of those with Alzheimer's disease, people fail to see that Alzheimer's disease and caregiving go together, hand in hand.

Now I am my mom's sole carer. This is a complex task; one that is often underplayed. It is physically and mentally stressful, due to the complexity of emotions (including resentment), the anticipated loss of a loved one, and the loss of income. It also involves loss of free time, and neglect of friends and hobbies. This often manifests as social isolation, with a consequent decrease in the quality of life. We, the carers, also age alongside the person with dementia.

Furthermore, the caregiving journey experienced by a family member significantly differs from that of externally hired carers. As family members, we are emotionally involved. For example, every day I go through the five stages of grief: ANGER – DENIAL – BARGAINING – DEPRESSION – ACCEPTANCE. When I go to bed at night, I have to accept the fact I can't change what is happening – all I can do is come up with ways of dealing with it. For example, being familiar with carer tactics means I can learn how to manage things better.

My mom is in the stage of the disease where she cannot function without me. I am at the stage in life where caregiving is a 24/7 job.

One can imagine the frustration of caregiving when I can't even have 10 minutes to myself. This is where Alzheimer's Disease Foundation Malaysia (ADFM) daycare centre comes in handy. It's a life saver. I was on the verge of breakdown – feeling so lost and lonely. But now, two or three times a week, I get some time to refresh, regenerate and recharge. With ADFM's daycare support, I am able to attend to my personal and marriage issues and I have more time and energy to plan my daily activities with mom. I am no longer angry or impatient. ADFM Daycare works wonders with mom too. She is happier and more active, compared with our mundane life at home.

As carers, we need support that goes beyond what has been provided by doctors, or hospitals. My wish for the future is for the government to allocate more funding – not only for research but also for the wellbeing of carers and for setting up more affordable daycare centres. Such assistance will help relieve the burden on carers and ease the journey of caregiving.

Thank you. ■

THE MALDIVES

When Alzheimer's 'kidnapped' mum: a daughter's pain and pleasure

Madam Aishath Moosa Didi was 89 when she passed away. A senior consultant pediatrician, Dr Rukhsana Ahmed reminiscences her mother's dementia journey.

Alzheimer's is a nasty disease. Like a cruel dictator, it kidnapped my mum and held her hostage for a number of years. This gradually took a toll on her memory, her personality, and her ability to carry out daily activities. Watching her being victimized by dementia also caused emotional turmoil, both for me and my sisters.

Mum was an adorable and affectionate person. She was considerate to others, loving and caring for her daughters. She did her chores without any negativity.

She was known among the family for her habit of chewing betel nuts. These nuts and their accompaniments – cloves, cardamon, lime and cut tobacco leaves soaked in water – she kept in a box known in Dhivehi language as the *"dufaa foshi."* The *dufaa foshi* was her greatest treasure. It was also the item with which family and friends fondly identified her. All her selfless characteristics made her the most lovable matriarchal elder in the family. Sadly, it all changed when dementia kidnapped her.

Despite being entrapped, and while Alzheimer's was taking her backwards down the steps of eight decades of life, the gentleness of her character stayed with her till the end. She spoke softly and calmly in short phrases, which later changed to single words and finally to head nods. Some words she repeatedly kept saying were *"reethikoh" "nalakoh" "saafukoh,"* meaning "beautifully," "pretty" and "cleanly." These words represented mum in her best years. She always liked fine and exquisite things. She dressed beautifully, loved her perfumes, and took great care in keeping her surroundings spotlessly clean. Because these qualities were so much a part of her nature, she willingly allowed us to shower her and dress her, and she would wait patiently for a spray of perfume when she lost the ability to independently do these tasks.

In retrospect, we realised we'd first noted changes when she was forgetting some of her prayers and needed prompting to complete the recital. Around the same time, she started talking about imaginary people standing by her bedroom window, watching her. All this was very much out of character. Being the doctor in the family, I personally dreaded to think what this could lead to, but once we had consulted the physician, a diagnosis of Alzheimer's Disease was confirmed. It was a life changing day for me. Tears filled me, not because I had to decide to relocate to Malé – from my life abroad – to be with mum, care for her and support the family, but because I could foresee the malicious trap dementia had laid on the path ahead. Given my hectic working life, I had never thought that a day would come when I had to be mum's carer. Yet unforeseen it came, and it transformed our lives forever.

Watching her in the grip of dementia was painful. However, caring for her was a pleasurable challenge. I was not a Geriatrician, and I was no expert on dementia, but I started reading, researching, and networking with colleagues to learn more about this brain degenerative disease. Unfortunately, at that time in the Maldives, few people knew what dementia was and there was no dementia support group or forum to turn to for help. For example, relatives or friends would ask about mum's status, and when I'd answer, *"She doesn't know us (her children),"* or *"We have to bath, feed and dress her,"* most people would look sad, assume she was in a coma, and wouldn't know what more to say.

In those moments I took the opportunity to tell them about dementia. I would explain, *"She is conscious. It is her memory that is fading, and she forgets how to do daily tasks, which is part of her illness."* Others would ask *"Isn't medication helping her?"* I would tell them that there is no cure for Alzheimer's disease, but there are drugs which can control the progression of dementia and add some quality to life.

While improving my caregiving skills, I also have a better understanding of mum – her character – her ways: aspects I was unaware of, as I had spent the greater part of my adult life away from her. However, I soon learned that I shouldn't lose myself and my work despite my primary focus being on mum. This is an important thing for the carer of a loved person with dementia to remember, particularly as it helps keep the emotional rollercoaster at bay. However, there were times during the daily routine of her hostage years when I felt emotionally drained and isolated because I was witnessing her progressive cognitive decline. Compassion fatigue, combined with a sense of helplessness and hopelessness would pass through me. To overcome it, I consoled myself with the joy of being able to care for mum when she needed me most. There were also fun times. Mum would randomly say something amusing, though completely unrelated to the moment, and we would laugh with her.

When I came to her bedside, she had a habit of holding my hands; her look being one of unspoken communication. Her touch always sent an electrifying current of the maternal bond through me. I would silently think: *"These were the hands that once carried me, fed me, washed me. They helped me walk and taught me to stand up and live my life."* Sadly, we were now in reverse gear – my hands doing those same things she did for me, helping her feel comfortable and pain free. Many times I wondered what would be going through her mind. In those unspoken moments, I could sense she knew I was her daughter although she may not have recalled my name. Indeed, in the end I understood that it was not the name that mattered, but the simple act of human touch – a tactile sensation which worked both ways; my hands giving her comfort, security, and love; her hands transmitting lasting, unconditional love.

Based on my caregiving experience, I feel there is an urgent need for an dementia support group in the Maldives. Recently, the Alzheimer's Society of Maldives has been established here, and there are plans for future support group activities. This forward step will benefit the carers of loved ones with dementia. They will be able to get information and advice, share experiences and seek help, which in turn will enhance their coping skills and reduce levels of stress. ■

THE PHILIPPINES

Dementia is challenging, but no regrets…

Madam Zenaida Z. Reynes was diagnosed at 78 in 2008. She was 92 when she passed away in January 2023. Cynthia Z. Reynes, daughter and carer, recalls her meaningful experience.

My journey into the world of dementia began in 2008. My mom was 78 years old. I was in my 40's. At first, I attributed my mom's forgetfulness or absent-mindedness to ageing. She would forget a friend's name, misplace her money, repeatedly ask the same question, or forget what I just told her five or ten minutes ago. I would reprimand her at times, but it went no deeper than that.

When a good friend told me that my mom may just have a "little bit of dementia," I felt so relieved that I ruled out

Alzheimer's disease. I pushed mom's symptoms to the back of my mind and told myself that things would be better tomorrow.

Years passed. I noticed that my mom had difficulty finding words, identifying, or recognising days of the week, the current month, and even recognising familiar faces. She would appear to be perplexed about her things or our home. I pushed her to maintain her independence. I preferred to think that she was just not trying hard enough or alternatively, that she was simply provoking me. I had plans. I had dreams. Obviously, I was in denial. However, her personality changes and cognitive decline meant it was time to visit a doctor. When it was confirmed that my mom was in the early middle stage of Alzheimer's disease, the news broke my heart.

During the early to middle stage of the disease, I had to deal with a lot of the typical dementia behavioural changes, including repetition, paranoia, accusatory behavior, and aggression. My mom would often misplace things and would accuse our household helpers of stealing. Her many mood swings resulted in a high turnover of our staff, till it reached a point where it was just down to the two of us. I have gone many times

without sleep because I tried to stay alert to my mom's every need, especially at night. I would worry that if left alone, she would slip or fall, or that she would just be up the whole night.

However, it was her aggressive behaviour that really brought out the best and worst in me. I didn't know then that I was experiencing temper meltdowns and was in one of the toughest stages of dementia care. They say temper meltdowns happen; that I would not be human if I didn't snap under extreme pressure once in a while. When we explode from the intensity of all the combined emotions and are overcome with guilt afterwards, we suffer not only mentally and emotionally, but also physically. However, I learned that it's best to accept the probability of a temper meltdown, as anything else would be unrealistic.

We know that the severity of Alzheimer's disease is daunting. The burden is enough to drive you to despair. The disease has the power to irrevocably alter the life of a patient, as well as the lives of the family members. As my mom entered the late middle stage, she continued to slide downhill. She went from having difficulty in finding words to making up words, before struggling to say anything at all. Finally, she lapsed into silence. Aspiration pneumonia was a common occurrence until her cardiologist recommended having a percutaneous endoscopic gastrostomy (PEG) procedure. We knew PEG feeding would not lengthen or improve the quality of my mom's life, but there was no other way to address her nutritional needs.

The milestones of an elderly can be grim. Simple tasks like changing my mom's clothes, combing her hair, or putting on makeup are just some of the invariable reminders of her decline. This reminds me of most kindergarten or nursery schools when they celebrate an important and exciting milestone for their preschoolers with a moving-up ceremony. I can just imagine the joy and pride that parents feel upon seeing their child march onto the stage. I wish I could say the same when we moved up to using adult diapers, nutritional food, diaper rash powder, and baby bath soaps for my mom. But who am I to complain? My mom gave a lot of her time and energy, too, when she took care of me as baby. In time, I know the day will come when she will be bedridden, and the mere mention of the word "final" or "late stage" would signal that my mom's time is approaching.

In 24 April 2022, we rushed my mom to the emergency room. An x-ray and other laboratory tests showed that she had aspiration pneumonia again and she was having atrial fibrillation episodes.

"Ma'am, I admire you for your patience in taking care of your mother. I just want you to know that she is now progressing to the very late stage of Alzheimer's disease," the doctor says. It was difficult to stop my tears from welling up. I knew this moment would come, but I had hoped against hope that is would not be this soon. I slowly walked back to the room, gave my mom a kiss, and silently cried. The clock was ticking and there's no stopping it. We brought her home and continued the care – the best we could possibly give her. While we were able to celebrate Christmas and New Year, my family was confronted with questions, such as *"Will this be the last time?"* and *"Will we see her again next Christmas season?"*

Sadly, it was at 12:35 PM on Friday,13 January 2023, my mom took her last breath, peacefully at home. Though she had long been gone – Alzheimer's did that to her – at 92 years of age, by God's hand, this was a good time to rest. Caregiving may seem a thankless task, but I have no regrets caring for my mom. Our love and the bond between us deepened, and I believe all those challenges I face will bring rich life-affirming rewards. ■

SINGAPORE

Once a fighter, always a fighter

Peter Estrop (63) was diagnosed in 2020, at 60.

Still a fighter at heart
My name is Estrop Ronald Peter Hugh, but I'm known to friends and family as Peter. I am 63 years old, and I am living with dementia. By no means has this journey been easy or straightforward. However, with my wife Evon by my side and with support from the community, there is much I find happiness in these days.

I cycle regularly, tend to our houseplants, and walk our beloved dachshund, Camo. I spend time with my family, especially my dearest granddaughters, Maia and Maesi. Their love reminds me every day that I may have been dealt a tough hand, but I am strong enough to face whatever comes my way, head on. Together with

Evon, I am embracing my golden years on our terms. This is my story.

A fulfilling career

I joined the 1st Commando Battalion of the Singapore Armed Forces (SAF) on 17 January 1978 and was enlisted as a National Service (Conscription Order) soldier. That marked the start of my 37-year career with the SAF. The journey definitely had its ups and downs, but I loved every second of it. I was part of a professional unit and had steadfast teammates I could rely on. In 2003, I was awarded "The Efficiency Medal" and "The Long Service Medal" – two glorious testaments to my mettle.

It was indeed with immense pride and joy that I served the nation all those years. I was also extremely fortunate to have the support of my wife, Evon, especially whenever I was overseas. She would single-handedly hold the fort and care for our four children. Never once did she call me during those periods – no matter the situation, she would handle it. All she would tell me was, *"Take care of the boys and yourself, train well, and be safe."*

I retired from uniform service as a Commanding Officer of the Special Operations Tactics Centre with the Rank of Chief Warrant Officer. I was then given the opportunity to work at the SAFTI Military Institute, in a unit called the Institute for Military Learning. There, life was good, and my work was fulfilling. Little did I know that a huge upheaval was on the horizon.

Life threw me a curveball

It started with the little things. I would have uncontrollable mood swings, which would leave me snapping at Evon for no apparent reason. I would want to head to the supermarket but could not recall how to get there. This was confusing and frustrating, and I knew that it was the same for Evon.

In late 2020, I was diagnosed with Alzheimer's disease. It was the biggest shock of my life, and nothing could have prepared me for it. I had always been active and health conscious. It didn't make any sense. Evon cried when I received the diagnosis, perhaps because of how daunting the future suddenly seemed, or maybe it was regret and anger at having chosen to delay our retirement, placing work first our entire lives. The months which followed were filled with denial and grieving. We had no idea how to cope.

The turning point

Through a medical referral, we were introduced to Dementia Singapore and in particular, its Voices for Hope (VFH) program, which aims to bring people with dementia and their care partners on a self-advocacy journey through empowerment. At VFH, we meet others on a similar path to ours and it was very good to know we were not alone. It was through VFH that we also finally got the much-needed information and answers we so desperately sought. This really helped us move forward on our journey together as care partners.

My days in the Singapore Armed Forces.

VFH instilled in me the confidence to go out and share my story with others. This helps diminish the stigma surrounding the disease and also helps others who are newly diagnosed, so they can know that despite dementia, life can still be purposeful and enjoyable.

Stepping up, speaking up

Today, Evon and I are extremely active in the dementia community, lending our voices to make a difference. We have committed to being advocates for those impacted by the condition and have, by invitation, shared our lived experiences with corporate audiences, community events and even at a local school. We have taken part in focus group and panel discussions. This includes a post-film panel discussion following the launch of a film titled ‘1000 Cranes’ by Dementia Singapore, as part of World Alzheimer’s Day. During a focus group discussion with the Housing & Development Board of Singapore, we also shared our views and recommendations on how to make public housing more dementia inclusive.

Recently, we appeared on Singapore’s news channels. This included an **8 World Spotlight** on early onset dementia, and a CNA two-part documentary titled “Sing to Remember: Defying Dementia”. In the latter, together with 8 other people living with dementia and their care partners, we trained as a choir, then put on a Christmas Concert in Orchard Road, Singapore’s busiest shopping street. Through such efforts, we continue to prove that even with dementia, we are living life to its fullest. ■

SINGAPORE

The love that endures

Rodney Paglar (63) was diagnosed in 2019 at 59. Jacinta Conceicao, wife and care partner, shares her journey of caregiving roles.

I once heard a carer share that being a carer is not a choice we make, but one that was made for us. I have been chosen to take on that role twice in my life.

My name is Jacinta. I've been married to Rodney for 31 years, since 1991. He is my best friend, my confidante, and my care partner on our dementia journey. We have been blessed with 2 children, Luke, who is in his 20's, and Timothy. Timothy was born with special needs. He had spastic quadriplegia and epilepsy. Following his birth, I decided to stop working for the very first time and become a full-time mum and carer. Timothy lived till he was 16. He passed away in November 2012. At that time, Rodney and I were both in our early 50's.

A double whammy

I've always known Rodney to be an enigma: witty but introverted. With him around there was never a dull moment. However, in the last year of Timothy's life, I realized that Rodney was becoming increasingly passive and leaving a lot of the decisions about Timothy's palliative care to me. It was tough, having to deal with feelings of grief and loss alone. While my husband's behavior was perplexing, I never imagined that there was something medically wrong with him.

Over time, Rodney started to display signs of forgetfulness. He had difficulties reading and writing, and problems accurately articulating his thoughts. Although a safety coordinator for a private construction company, he began taking sick leave whenever he had to give a presentation. He would even bring home workers' time logs for me to complete, as he could not remember how to write numbers or words. When his contract ended in 2018, he stopped working altogether. While previously self-confident in any situation, as the days passed, he became more and more anxious and withdrawn.

The diagnosis

A couple of months later, during a regular medical check-up, a family doctor referred us to the National University Hospital (NUH), Neuroscience Department, for a formal diagnosis. A CT scan revealed that Rodney had Alzheimer's disease. This was in August 2019. He was 59 years old. What followed was a flurry of emotions – shock, confusion, and despair. I had always looked to Rodney as my rock – someone I made my life plans with – someone I could turn to for answers in challenging times. From the look on his face when he heard the diagnosis, I knew that this time he had no answers. It was the first time I ever saw him cry. These were tears of frustration, anger, and loss. I realized I had to stay strong for him and support him, ultimately stepping into the role of carer once again.

A silver lining

Rodney got his second diagnosis for Alzheimer's Disease after he had a lumbar puncture at the National Neuroscience Institute (NNI). It was through the NNI clinic that we were linked up with Dementia Singapore, its programs, and services. I truly see Dementia Singapore as a beacon of hope and light, guiding us on this unprecedented journey. We joined the Voices for Hope (VFH) empowerment program, where we met other families from the dementia community. Through VFH, we made many new lifelong friends. With the support of the organisation and other carers, we were able to get more information about how to better care for Rodney. This was also the first time in ages that I saw Rodney emerge from his shell a little, laughing and interacting with others. Things no longer seemed so hopeless, and we started to incorporate the knowledge we gained from VFH into our lives.

Navigating tough times

Unfortunately, the COVID-19 pandemic in 2020 proved to be a catalyst for a significant deterioration in Rodney's condition. Restrictions seriously disrupted his daily routine, with family outings, outdoor exercise, and swimming all off the table. I would attempt to keep him occupied by getting him to help me around the house, tend to our little garden space, or even teaching him to take pictures on his mobile phone when he went for short walks. While this helped to keep him engaged during Covid, he nonetheless emerged more reserved and unsure of himself post-lockdown.

These days, Rodney experiences hallucinations and increased anxiety. Some days, he does not even recognise me, and he can no longer recall my name. My current focus is getting him to stay healthy – to eat well, have enough rest, and exercise. I continue to take him on nature walks and keep up visits with family members. Sometimes, I use old photographs to jog his memory and even a mere flicker of recognition in his eyes is a win! In my spare time, I find it deeply therapeutic for me to advocate for the dementia cause. It is a privilege for me to be able to share the ups and downs of my dementia care journey and hopefully inspire others in the same situation to take things one day at a time – just as I do with Rodney.

Till the end of time

Despite the challenges he faces in vocalising his thoughts, it does not take much for me to understand him these days. We have a lot of history together. There are still brief moments when I catch a glimpse of the Rodney I first met in 1985. These moments are precious, and I hold them dear. I am fortunate, too. Despite his condition, Rodney still recognises my need to recharge when I am feeling tired or drained. Though a little apprehensive, he allows me the time and space I need to do this. On other occasions, without any prompting, he suddenly gives me a quick kiss or a hug. Furthermore, he remains sensitive to my feelings. His simple 'thank you,' 'I love you,' or 'I'm sorry' reminds me that our love transcends all else. So, for as long he needs me, even till the end of time, I will be here, supporting him. ■

SRI LANKA

Face to face with the unthinkable

Dr Deepthi Amunugama, son and carer for Madam Podimenike Amunugama (91, a cancer survivor) shares the story of his mother's dementia journey.

It was around 2018 when the early signs started emerging. My gentle mother suddenly became suspicious of the housemaids. Initially, I just replaced the maids, but when my mother's irrational behaviour persisted, I realised it was due to mild paranoia. Being a doctor, my medical training soon kicked in. I had my mother examined by a colleague: a psychiatrist. This meant we obtained a formal diagnosis of her dementia and had access to necessary treatment. However, she soon began to show additional symptoms of the disease. These were further exacerbated by my father's illness, which saw him bedridden for a short while before he passed away.

Theoretically, I was well aware of what to expect, and I understood the natural progression of the disease. Despite this, my mental reaction – as a son and as main carer – took centrestage. I questioned why this calamity had to happen to my mother: someone who, for years, had served the government, managing one of the largest oncology units in the country. Had she not survived and overcome cancer and been in remission for over 30 years? I ran through the whole gamut of emotions, and my belief is that all family members of dementia patients share this same experience. The knowledge and understanding of what to expect does not lessen the burden of the illness, nor does it really make any difference when we come face to face with the unthinkable.

Even as I struggled with the emotions and depression that family members often face in light of a dementia diagnosis, I was committed to ensuring that my mother got the best treatment possible. This was the time she needed me the most and I was going to do my utmost to ensure she could stay in her own home, with 24/7 care.

This was much easier said than done. Being an only child, without a large extended family with whom I could share responsibilities, meant the role of the main carer fell to me. My job as a surgeon meant irregular and long hours. Furthermore, as I worked exclusively in Government service, rather than in private practice, I did not have limitless financial resources.

Like many in Sri Lanka, I was faced with a lack of structured support and trained professional carers, as well as deficiencies in social welfare for patients living with dementia. My mother's case was further complicated by the fact that she had undergone a permanent colostomy during her battle with cancer and had a stoma bag. She also had a neuropathic leg, which made her gait unsteady. Most carers lack training in the skills required for such cases, especially when care includes dealing with the symptoms of dementia, such as psychosis, delusions, etc.

I am fortunate that my network in the medical fraternity gives me access to those who can provide this training, but the rapid turnover of carers means this process is endless. There is simply no institution or organization that offers these services, so it is up to the family to be 100% involved in the process of proper care – despite having little opportunity to step away or take a much-needed break from full-time supervision. Sri Lanka desperately needs infrastructure and social support that provides professional, customized advice on the care for each patient, but which, at the same time, is in financial reach of the individual's family.

I try to provide my mother as much social interaction as possible. I have found that social events are less stressful when I give others a 'heads up' on her situation. I explain that she has a medical condition: one causing her to behave in a way whereby she is not 'herself.' It pains me that people see a very different person from the confident, caring

I try to provide my mother as much social interaction as possible.

professional my mother used to be, and simply think she's 'insane.' I am well aware that many feel compelled to keep their loved one confined at home to avoid their being mistreated or misunderstood in public. However, this leads to even further social isolation and provides no break for the carer.

Since she started attending the activity centre managed by the Lanka Alzheimer's Foundation (LAF), I found that my mother's interpersonal skills and use of her hands (to write, draw, use implements etc.) have improved significantly. Perhaps because she meets different people outside her usual circle of family and carers, she is less introverted. When I tell her she is going to LAFS, there is a marked sense of anticipation and positive mood enhancement. The benefits have been immense and provide more for her than anything either I or her carers have to offer. Yet again this reveals the significant difference structured care and trained support can make to the lives of both patients and carers.

My journey has not been without many personal sacrifices. My mother's illness and lack of specialised support has meant that my career and personal life have had to take a back seat. It is impossible for me to be absent for any extended period, for additiona training or exposure overseas, though both are critical to my progression in the field of surgery. But, I have no regrets. I am just grateful that I can be there for my mother, as she has made me who I am today.

Even though I have many advantages because of my medical training, access to information and financial resources (though, under the circumstances, the latter are somewhat limited) I often still feel that I'm alone in my battle. I feel that the help my mother gets is inadequate and that it is far from what I would ideally like to provide for her. I simply can't imagine the plight of families who have no basic knowledge, who lack support and who must also deal with issues of social stigma, despite their having few, if any, coping skills or strategies. ■

TAIWAN

A brave woman's words on dementia

Amy Su (74), an artist and retired elementary school teacher, was diagnosed in 2011.

Hello everyone, I am Amy Su. I am 73 years old. I am a painter, a retired elementary school substitute teacher, and the mother of two daughters. Since 2011, I have had a new identity. Now, I am a "person with dementia."

First, I thought I was in some strange environment and couldn't remember how to get home – even though I went the same way every day. Then, while reading, I went completely blank – words and sentences made little sense. Finally, while preparing food, I would often cut my fingers. I even put my bare hands into the hot pot to scoop up the noodles! Accompanied by my husband, I went to the doctor, and I was diagnosed with "Alzheimer's disease". This made me very depressed because I had seen relatives with dementia. I imagined that, in the future, I may have problems walking, or difficulty swallowing, and I might forget my beloved family members. I even thought that I could be bedridden for a long time and that I might have to be force-fed. I felt very sad, and I worried about being a burden to my husband and children. I even wanted to end it all.

My family's love encouraged me to bravely face the disease

With my husband's encouragement, I read many books on dementia so I could better understand its causes. I realized that I must be self-reliant in facing this disease and help myself delay its progress. In addition to taking medication on time, I changed my daily eating habits and became more active in learning new things. I even signed up for a singing class sponsored by the Farmers' Association. Because I am a lousy singer, I once told my husband that I didn't want to do it anymore. But he said, *"Keep singing, because you bring joy to people. You are a wonderful person!"* After that, the more I sang, the better it sounded, and even my classmates said that I improved a lot!

My husband has also paid a lot of attention to my safety and security. For example, when I take the MRT, he always prepares a map, and sends me a message reminding me to get off at the right time. Sometimes I have made small mistakes but asking passers-by for help can also stimulate the brain. After I was diagnosed with dementia, my sense of balance became worse and I often fell over, so my husband put anti-slip mats in the

bathroom and anti-slip strips on every step at home. He is very thoughtful, and I thank him for this.

Now that I am living a more active life, I have signed up for a home economics class. Recently, I decided to take Japanese or English classes and learn photography, as well as make and send 'day noon night' messages to friends. Because the warmth of my family's love encouraged me to face dementia, I am trying to ensure I don't deteriorate too quickly.

Breaking the bonds. I have dementia but not demoralised

At first, having dementia really, really scared me. I had learnt traditional Chinese painting (landscapes, flowers, birds, figures) for more than 20 years, and I also taught art. After I was diagnosed, I stopped all activities. I didn't want to go anywhere. I stayed home the whole time. I was afraid of saying the wrong thing – doing the wrong thing – offending others. But now I invite my neighbours to my house to make tea, taste tea and talk about anything under the sun. I read newspapers and magazines, join in singing classes, and continue to paint traditional Chinese figures. I also participate in the Taiwan Alzheimer's Disease Association advisory group. I try my best to exercise frequently, be self-reliant and self-improving, and make sure I don't progress too quickly. I find that I can achieve a lot and I want to tell everyone that people living with dementia can continue to do things that are actually beyond one's imagination. Despite dementia, we are not demoralised. We still have unlimited potential. Let us break the bonds and defeat dementia together! ■

Amy Su's watercolour painting is on the eBook cover.

TAIWAN

The pearl necklace of dementia

Madam Pai Wan-Chih (74), primary carer to her mother with dementia, was herself diagnosed and has been living with dementia since 2016.

Hello everyone! I am Wan-Chih and I graduated from the Department of Special Education of Taipei Municipal Teacher's College. After graduation, I taught in junior high and elementary schools for 28 years. Some of my beloved children and lovely grandchildren live in Japan, and I miss them very much.

At the beginning of 2013, I noticed that my mother was behaving abnormally. She went to the doctor and was diagnosed with dementia. In the following days, while taking care of my mother, I too realized that I had similar symptoms. For example, a rag I had just used disappeared. I couldn't find it – no matter how hard I searched. So, I went to the doctor too, and I was diagnosed with mild dementia. It was in April 2016. For a long time, I couldn't accept this news and I shut myself off, but, one day the pastor came to my house to pray for me. That was when I realized that my mother still needed my care, I couldn't drag my children down, and I couldn't give up on myself.

I began to actively participate in cognitive training and many other different activities. I went to the elderly service centre to participate in brain health, art creation and Taiko classes. I also joined the Japanese folk dance and sign language dance classes. I met a group of like-minded people and became good friends with them. Together we participate in public welfare performances, even travelling to Japan for cultural exchange.

Advocacy for dementia rights

In 2016, I joined the Taiwan Alzheimer's Disease Association (TADA) dementia advisory group. Two things made the greatest impression on me. The first one was being able to participate in the dementia-friendly MRT initiative. At that time, I found the font used in signs in the stations was too small, and the arrows used for showing direction were unclear. This meant that oftentimes I didn't know where to go. I discussed this with TADA and the advisory group members, and suggestions I made to government resulted in big improvements in this area. The second one was to create, with the advisory group, the "Cherish Memories Calendar". We included various features to make it suitable for people with dementia; for example, we used pictures that corresponded to the seasons and enlarged the date grid. Also, we were able to share this calendar with numerous organizations, as well as with our friends. Everyone loved it, raved about it and pre-ordered one for the next year!

As dementia is not the end, embracing people is really important.

After being diagnosed with dementia, my memory has gradually been lost. I find this very distressing. It's like a pearl necklace with broken strings – the pearls scattered on the ground. But then I figured it out. Just as each pearl is precious, so too is each memory. And, I don't need to force myself to string either the pearls, or the memories, together again.

I want to tell everyone that dementia is just the disappearance of a certain part of life. Although it's an inconvenience, God sends many angels to help. If you suspect your relatives or friends have symptoms of dementia, please be more caring and tolerant. Early dementia patients may not even know they have a problem. Therefore, please encourage them to seek medical examination as soon as possible, so they don't miss the golden opportunity of early treatment. In addition, people living with dementia need to stay active in order to delay deterioration. The government and many social groups have valuable resources to help people living with dementia, but not everyone has this information. I hope that, in the future, there will be more publicity to raise awareness of dementia and available treatment. ■

TAIWAN

Not even dementia can stop me

Tseng Ching-Fang (74) and his wife are living with dementia. They were both diagnosed in 2016.

Hello, I am Ching-Fang. I have worked in plastic electroplating for 50 years! I was diagnosed with dementia in 2016 and I am honoured to be invited to share my experience.

At first, it was about my wife. She would repeat the same question, over and over again. I began to ask myself if she was suffering from dementia, but I was worried that she would not go to the doctor. I didn't want to hurt her feelings or self-esteem, so I said: *"We are getting old. Let's go to the hospital for a check-up together."* Surprisingly, my wife and I were both diagnosed with Alzheimer's Disease. I was astonished. I had no symptoms whatsoever, and my job performance was all good. I wondered how this was possible. But, since the disease had been discovered, I had to deal with it.

Optimistic, positive and calm in the face of dementia

After realising I had dementia, I didn't want to let myself deteriorate, and I didn't want to be a burden for my daughter. So, I scheduled activities every day, and sometimes even in the evenings. My wife and I also participated in courses run by the dementia center, including brain exercises, muscle endurance exercises etc. Different classes were arranged in the mornings, from Monday to Friday. My wife needed to rest in the afternoon, so once a week I arranged for myself a yoga class, which was run as a volunteer service. In the evening, I also joined a Waidan Gong class (once a week) and attended Tai Chi and reading club (twice a week). While my wife attended classes at the center every morning, nothing else was scheduled. This was due to her lack of physical strength as much as her disinterest in any other activities. Life continued like this for two years, then we had another assessment. The doctor told me that I had greatly improved. I no longer needed to take medicine – I just needed a follow up. However, my wife's condition was different. Her symptoms had not improved, and she had to continue with her medication.

My experience is that, in addition to taking medicines on time and returning to the doctor for regular treatment, it is also necessary to exercise diligently and participate in group activities. This is very helpful in delaying the deterioration associated with dementia. Now, not only can I manage the big and small things in my life, but I can also take good care to my wife. Furthermore, I don't need to worry about being a burden on my daughter.

Change and hope

I joined the advisory group of the Taiwan Alzheimer's Disease Association in 2019. We have a meeting every month and discuss issues related to dementia. I used to be afraid of speaking out. Now I am brave enough to express my opinions. I was not willing to face dementia. Now I am willing to stand up and speak out! In 2020, I shared my life publicly for the first time, at the World Dementia Month event. I shared my feelings and my experience in the hope that I could help others. In reality, I was the one who benefited. For example, I am no longer afraid of other people knowing that I have dementia and I can see things now from various perspectives. This is so different from my previous experience, including at work.

My sincere advice

If you or someone in your family is thought to have symptoms of dementia, please seek help and medical treatment as soon as possible and encourage them to do the same. If the diagnosis is dementia, the symptoms are very mild in the early stages, so don't worry! Please follow the doctor's instructions. Take the medicines and return to the clinic regularly for treatment. Also, please take advantage of your good health to participate in groups, classes, sports, and volunteer activities. This can help delay the progress of the disease. It might be not easy at first, but it will gradually get better and better! This is my experience. This is what I want to share.

Thank you. ■

VIETNAM

Love, compassion and unlimited patience

Madam Hanh Nhu (83), diagnosed in 2019, is cared for by husband and care partner, Mr Khiem Dang who is 88. Ms Thu Ha Dang their daughter shares their story.

Hanh Nhu shares her thoughts...
What is dementia? I have no idea. Everyone tells me that I have dementia, because my memory gets worse day by day and I have some strange behaviours. My children and grandchildren don't let me do anything. This includes the cooking. Maybe it's because there were a few times when I forgot to turn off the stove and burned the food. Sometimes I add too much fish sauce, which makes the soup too salty. I love going to the market every day and think it's an indispensable part of Asian women's lives. But ever since I had a stroke, half of my body has become

weak, and my children won't let me go to the market any more. They also complain that I am becoming more and more difficult to please. They say I'm often irritable, sulky, and crying for no reason. My husband is the person who loves me the most, but he also says that my personality has changed a lot…

All this makes me feel very confused because I think I'm completely normal. I am 83 years old this year. Anyone my age is likely to forget things from time to time - never mind the fact that I've had many ups and downs in life and dealt with some serious illnesses. I spent the days and months of my youth living amongst the bombs and bullets of the two wars, against France[1] then America[2]. When I was a student, I was crowned Beauty Queen at the Hanoi University of Science and Technology. After university, I was able to do my apprenticeship in Bulgaria and Germany, thanks to my excellent academic and work achievements. But hardships faced during the war, deprivation of resources during 'The Subsidy Period'[3], two difficult births, two rounds of cancer (breast and colon), and most recently, a stroke (in 2019) have exhausted my health. This might explain why sometimes I'm not as lucid as I used to be.

Even though I'm no longer strong and healthy, I want to live a meaningful life in my old age. I no longer earn money, but the last thing I want to do is become dependent on the people around me. I want to do chores around the house to support my children and grandchildren. I want to go out, meet other people, and see my beautiful and dear Hanoi city in autumn. I don't want to sit at home from morning to night and do nothing. Sometimes I meet up with old friends and neighbours, but it's obvious to me that they just pity me. They say I have lost my mind. I am very sad, incredibly worried, and sometimes I feel hopeless. Will I still know who I am after a while? Will I still recognise my husband, children, and grandchildren? Can I live until my grandchildren have grown up, gotten married, and had children and grandchildren? The field of medicine is getting better and better, so is it possible to cure my dementia? Will society help people like me? I just want to be able to live and live meaningfully!!!

Khiem Dang, husband and care partner shares...

My wife is the most wonderful woman in the world. When she was young, she was very beautiful and gentle. She loved her husband very much, loved her children, and was good to everyone. She forever made sacrifices, accepting only the smallest things for herself so that others could be happy. She was always like that, both at work and at home. For example, during the war she donated lots of blood to wounded soldiers - to the point where she fainted. Although she is a small person (only 40 kg and 1.53m tall) she also dug and lifted hundreds of bags of soil (each weighing 30 to 40 kg), building shelters to protect people against bullets and bombs during the war against America. Maybe it's because of her way of life that she wasted too much of her health and didn't take good care of herself. As a result, she's had cancer twice,

Even though I'm no longer strong and healthy, I want to live a meaningful life in my old age.

was operated on 5 times, and has suffered from hemiplegia.

After a stroke four years ago, her memory has been getting worse and worse. Her temperament has also changed. Sometimes, I can't tell whether she is the same gentle wife I knew before. I realised that the situation was deteriorating. At first I just thought, "She's old now. Everyone forgets things from time to time. It's possible that after the stroke, part of her brain no longer works well." But as the days passed, I could see that she was definitely not ok.

She is not aware of her situation and still thinks she is completely normal. In reality, she has been in a wheelchair for four years, and caring for her has become increasingly difficult. Meals take hours. She sucks on the rice and refuses to swallow. At night, she often wakes up and cries because she remembers events that happened decades ago. She gets angry, blames me for things that didn't happen, and doesn't let me take care of her… Honestly, sometimes I feel completely exhausted, and I don't want to live anymore!

My daughter is a doctor, and she took her mother to see a specialist. She told me that my wife was suffering from dementia. She also printed and gave me many documents about the disease. I have read them all. In fact, I even went out to find and buy more books on how to care for people with dementia, although I must say that these books are extremely rare in bookstores. In Vietnam, most ordinary people like me don't know about this disease. They call people like my wife insane, crazy...

Now, after four years, I have learned a great deal about the disease and accumulated quite a lot of experience in taking care of my wife. I think that caring for people with dementia will vary, as every case is different. But I also want to share my own experience, in the hope of helping those in the same situation as me, so here are my thoughts:

1. The care of loved ones is extremely precious, because the carer understands better than anyone else the patient's personality and preferences. Most importantly, they take care of the patient with love, compassion, and unlimited patience.

2. The person living with dementia is at the centre of care: all carer activities need to be constantly adapted so that they remain patient focused. When they are happy, we laugh with them. When they cry, we have to pretend to cry too. Eating together, sleeping together, and exercising together will make the patient more motivated.

3. When the person is in quite a ‘normal’ situation, they are very sensitive. They are aware of the behaviours and attitudes of the people around them. So please be respectful, sincere, and loving – they will feel this.

4. As often as possible, find ways to engage the patient in real life situations. This will reduce the time that they spend thinking and worrying alone, which may easily lead them to panic.

5. Movement, movement and movement. Increase physical and mental exercise. Only in this way can the person regain function, both physically and mentally.

6. Communication! The ‘multigenerational house’ is one of the lovely cultural traditions of the Vietnamese people, whereby both older and younger people live together in the same house and support each other. This is very valuable for the elderly in general, and for those with dementia in particular. It especially applies when there are small children in the family – the elderly and young children having a spiritual connection that makes it easy for them to understand and sympathise with one another. Long-term friends are also an extremely valuable source of encouragement for the person living with dementia.

7. Carers need to know how to take good care of themselves and think positively. Only in this way can any of us take care of the person with dementia in the longterm.

8. Do not hesitate to share difficulties with and receive help from others. Having extra help will make the caregiving journey easier.

I love my wife! Perhaps LOVE is the biggest motivation. Along with constant LEARNING, this love has given me, an 88-year-old man, the strength and energy to take care of her for the past four years. It will continue to do so in the years to come. ■ ”

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[1] *The war against France (also known as the First Indochina war) was a conflict that took place between the French Expeditionary Force and its allied forces with three Indochina countries: Vietnam, Laos and Cambodia, in the period 1946-1954.*

[2] *The War against America (also known as the Vietnam War, or the Second Indochina War) was a conflict that took place between the United States, the Republic of Vietnam, the Kingdom of Laos, the Kingdom of Cambodia-Khmer Republic, and the anti-communist alliance against the Democratic Republic of Vietnam, the National Front for the Liberation of the South led by the Communist Party of Vietnam and its allies: Pathet Laos, Democratic Cambodia with support and aid from the Bloc of Socialist countries communism, especially the Soviet Union and China.*

[3] *‘The subsidy period’ refers to the period 1975-1986 in Vietnam. Most economic activities were paid for by the State at that time, this being a feature of the economies of the Soviet bloc countries.*