

— SINGAPORE HEALTH —
**INSPIRATIONAL
PATIENT &
CAREGIVER**
— AWARDS 2020 —



ABOUT THE AWARDS

Since 2010, the annual Singapore Health Inspirational Patient and Caregiver Awards honour individuals for their strength, courage and resilience in the face of health challenges, as well as outstanding patient support groups that have provided invaluable support to patients and caregivers.

Each year, our winners continue to inspire us with their ability to overcome adversity. Their experiences provide valuable learning for the doctors, nurses, allied health professionals and other healthcare workers who care for them.

This year, we recognise 45 winners who, amid the challenging COVID-19 pandemic, continue to motivate healthcare professionals to deliver better care and inspire many others with their zest for life.

PARTNER-IN-CARE AWARD

Research has shown that patients who are engaged in their own care and actively partner the healthcare team in their journey experience better health outcomes. To encourage patients and caregivers to take on active roles in their care, the new Partner-in-Care Award honours one winner from each of the Inspirational Patient and Inspirational Caregiver categories who has demonstrated this exemplary active partnership to improve care quality and experience.

Organised by



Participating Organisations



All photos in this book were taken before the COVID-19 pandemic.

Inspirational Patients 6

PARTNER-IN-CARE AWARD

Changi General Hospital
Ms Ai Ling Sim-Devadas 8

Bright Vision Hospital
Dr Hong Ya Lin 10

Changi General Hospital
Mr Dipak Meghji 12

Mdm Nai Poh Choo 14

KK Women's and Children's Hospital
Ms Abebi Chan 16

Ms Khusniwati Binti Md Mohani 18

Mr Raphael Lee 20

National Cancer Centre Singapore
Ms Daphne Tan 22

Ms Florence Loh 24

Mdm Sally Kok 26

Mr Shawn Loh 28

National Neuroscience Institute
Ms Sarah Low Kia Tian 30

Ren Ci Hospital
Mdm Barbara Tan 32

Sengkang Community Hospital
Mdm Hui Pui Pui 34

Mdm Sarah M Shakun 36

Singapore Cancer Society
Mrs Wendy Tan-Kuah 38

Singapore General Hospital

Mr Herman Ho 40

Mr Melvin Ong 42

Mr Ui Wun Juan 44

Mrs Viji Ramakrishnan 46

Singapore National Eye Centre

Mr Chandra Mohan s/o Narayanasamy 48

SingHealth Polyclinics

Mdm S. Sathamba 50

Sunlove Home

Mr Ang Kim Axe 52

Mr Cheong Leong Ching 54

Inspirational Caregivers 56

PARTNER-IN-CARE AWARD

KK Women's and Children's Hospital
Mr & Mrs Tee Meng Kem 58

Changi General Hospital
Ms Siti Nur Arina Bte Abdul Rahman & Ms Siti Nur Ariani Bte Abdul Rahman 60

Mdm Liaw Soon Fong 62

KK Women's and Children's Hospital
Mdm Julia Binte Kasiman 64

Ms Toh Shiling 66

National Dental Centre Singapore
Mdm Nagajothi Marimuthu 68

National Neuroscience Institute
Mr Nicholas Sim 70

Ren Ci Hospital
Mr Ng Buan Hian 72

Mr Riechard Ang 74

Singapore Cancer Society
Ms Amanda Pang 76

Singapore General Hospital
Ms Elaine Chiang 78

Mrs Wong Lee Yong 80

SingHealth Polyclinics
Mdm S. Supama 82

SPD
Mdm Farah Juwita Bte Alias 84

Mdm Seah Shiang Ping 86

St Luke's Hospital
Mr Tan Shew Sia 88

Sunlove Home
Ms Nur Azizah Bte Abdul Malik 90

Inspirational Patient Support Groups 92

KK Women's and Children's Hospital
Sugar Rush 94

National Cancer Centre Singapore
Brain Tumour Society Singapore 96

National Neuroscience Institute
CARE Programme Support Group 98

Singapore National Stroke Association 100



INSPIRATIONAL PATIENTS

PARTNER-IN-CARE AWARD

Ms Ai Ling Sim-Devadas

Dr Hong Ya Lin

Mr Dipak Meghji

Mdm Nai Poh Choo

Ms Abebi Chan

Ms Khusniwati Binti Md Mohani

Mr Raphael Lee

Ms Daphne Tan

Ms Florence Loh Suat Tin

Mdm Sally Kok Yuet Hoe

Mr Shawn Loh

Ms Sarah Low Kia Tian

Mdm Barbara Tan

Mdm Hui Pui Pui

Mdm Sarah M Shakun

Mrs Wendy Tan-Kuah

Mr Herman Ho

Mr Melvin Ong

Mr Ui Wun Juan

Mrs Viji Ramakrishnan

Mr Chandra Mohan s/o Narayanasamy

Mdm S. Sathamba

Mr Ang Kim Axe

Mr Cheong Leong Ching

“Three years on since my diagnosis, I can say with conviction that I am thankful to be able to use my experience with cancer to better the lives of other patients. In some ways, I think my cancer has been a blessing in disguise.”

Ms Ai Ling Sim-Devadas, 45
Healthcare Communications Consultant

The diagnosis of breast cancer in 2017 was a bolt from the blue. I went to see a doctor for pain in my left breast, but to my disbelief, tests found that I had cancer in my right breast instead of my left.

The treatment that followed was difficult, with the usual side effects that came with chemotherapy. What changed the way I saw chemotherapy was something that my friend said; she told me to imagine it not as toxic substances infiltrating the body, but as the healing nectar of life flowing through. From then on, I saw chemotherapy as a life-giving therapy for those who needed it. I started to acknowledge my treatment journey and came to terms with my cancer.

In March 2018, when I was warded for a bout of hives and fever from chemotherapy, I was approached to join the SingHealth Patient Advocacy Network (SPAN). It was a timely invitation, as I was contemplating what more I could do in life despite my illness. It felt right to give back for all the care I had received – and I accepted the invitation without hesitation.

I have worked in the healthcare setting for many years, but being a patient helped me truly understand the needs of patients. While healthcare professionals do a good job at providing clinical care, sometimes patients crave a deeper connection, and greater empathy and compassion. Being part of SPAN allows me to work closely with healthcare professionals and provide insight from the patient’s perspective.

SPAN has been actively involved in healthcare workgroups that look at improving the patient experience, through efforts such as the creation of patient materials and judging for healthcare awards. Last year, SPAN produced a Plain English Glossary to help doctors and nurses communicate more effectively with patients and caregivers without using confusing medical jargon. I also co-developed the

Patient Advocate Communications Training programme to help SPAN members communicate their perspectives clearly when working with healthcare teams.

With other SPAN members, I started Patient Experience Talks, or PEx Talks, for patients to share their stories and experiences. The talks have been well-received by healthcare professionals with requests to conduct more sessions.

As Co-Chair of SPAN, I am hopeful that our efforts will help improve the healthcare experience for patients. Three years on since my diagnosis, I can say with conviction that I am thankful to be able to use my experience with cancer to better the lives of other patients. In some ways, I think my cancer has been a blessing in disguise.

“

Ai Ling’s positivity and commitment to improving the patient care experience through her work with SPAN is really admirable. She has turned her illness into a blessing for others – leveraging her own experience to create programmes and lead initiatives that encourage patients, caregivers and healthcare professionals to work together to improve the overall care experience.”

Chang Sook Mei

Deputy Director
Group Office of Patient Experience
SingHealth

Deputy Director
Corporate Affairs (Patient Relations)
Changi General Hospital





“When I feel down, I always tell myself that the difficulties will pass, just like how dawn always comes even after a very long night.”

Dr Hong Ya Lin, 67

Lecturer, Singapore University of Social Sciences (SUSS)

I am a lecturer of Chinese Literature at SUSS, and a relief teacher at a local secondary and a primary school. In 2018, I was teaching when I fell down and landed hard on my left knee.

Although I was in great pain, I thought I just needed rest to recover. I was shocked when the doctor at Tan Tock Seng Hospital (TTSH) told me that I needed surgery for a fracture in my kneecap.

Deep down, I was terrified at the prospect of undergoing surgery. But I hid my fear because I was a pillar of strength for my family, and was always seen by others as a strong person. I kept my feelings to myself, though I broke down and cried a lot when I was hospitalised.

After the surgery, I spent 10 days, including my birthday, at TTSH. As I lived alone and could not manage on my own while recovering, I was transferred to Bright Vision Hospital (BVH) for rehabilitation.

I like to joke that I had a one-month holiday at BVH because I was so well taken care of by the BVH care team. Of course, I had to endure the pain of physiotherapy to get better, but life is sweeter after you have been through suffering.

When I feel down, I always tell myself that the difficulties will pass, just like how dawn always comes after a very long night. This is also how I got through the hardships in my life as a single mother of two.

I got married at the age of 21 right after I graduated from university. My husband passed away when our younger son was only two years old. To support two young children as well as my parents, I held multiple jobs and often worked 10 hours a day. I suffered yet another devastating blow when my older son died at the age of 30 from illness. I went through a very difficult time, but managed to pull myself together eventually after many years.

It was only in my 50s, when my life was more settled, that I pursued my Master’s degree and later obtained my PhD at 60. To date, I have written three Chinese self-help and poetry books. I give talks on topics like active ageing, mindfulness and positive thinking as I have a great interest in them.

During my stay at BVH, I shared about the importance of positive thinking with other patients. If they felt discouraged or unhappy, I would lend a listening ear and share with them about my challenges in life and how I overcame them.

My advice to patients and caregivers is not to give up. Always tell yourself that there is light at the end of the tunnel and you will get through the hard times.

“

Ya Lin’s zest for life is inspiring. At BVH, her hearty laughter and enthusiasm were contagious. She would lend a listening ear to the other patients and help them whenever she could, such as with translations or simply to cheer them up.”

Ng Bee Leng

Manager
Office of Patient Experience
Bright Vision Hospital



“It’s been two years since I suffered acute paralysis, and I have regained about 85 per cent of my motor skills. I am determined to recover fully and will not give up.”

Mr Dipak Meghji, 62

Businessman

I remember 18 January 2018 vividly. That was the day I had a fall in Singapore while on a connecting flight from India to Fiji where I live. I suffered head injuries and fractured my ankle.

I was rushed to Changi General Hospital (CGH) and warded in the Intensive Care Unit. Tests showed that I had Acute Motor Axonal Neuropathy, a severe variant of the Guillain-Barre syndrome. It is a rare disorder where my immune system attacks my nerves, resulting in acute paralysis and loss of reflexes.

For someone who was active and enjoyed sports, I was devastated to be a quadriplegic (paralysed in all four limbs). My wife, two young daughters, and extended family members were extremely worried, and it did not help when we learnt there was no cure for the condition.

Initially, I could not even lift my arms to feed myself and had to be tube-fed for almost two months. I had to re-learn how to do the most basic things, such as moving and balancing. Despite this, I never lost faith in God that I could recover.

I had to undergo intensive rehabilitation to regain my motor skills. My daughters returned to Fiji as we didn’t want to disrupt their studies, while my wife stayed with me in Singapore as I received treatment.

Dr Monica Saini from CGH was very encouraging during my recovery journey. She took videos and documented my progress, such as the time when I could first move my fingers. She would share my videos with other patients to motivate them, and this spurred me to work harder.

I spent almost one year in CGH and was later moved to Mount Elizabeth Hospital. In both hospitals, I received really good care and encouragement from nurses, doctors and therapists, in particular Dr Saini, Dr Chong Yu Eric Silvio and Dr Shrikant Pande.

With my wife’s help and encouragement, I went beyond the exercises recommended by my physiotherapists and occupational therapists. My wife and I spent four to six hours every day walking, swimming and training with weights. When I was finally able to take a few steps on my own in March last year, I was over the moon!

My Hindu faith also kept me strong. I visited temples in Singapore and made friends with other devotees who visited me and helped with my exercises. Their support and my wife’s tender care gave me the strength and motivation to press on.

I returned to Fiji in November 2019. Till today, I continue doing my rehabilitation exercises. It’s been two years since I suffered acute paralysis, and I have regained about 85 per cent of my motor skills. I am determined to recover fully and will not give up.

“

Most patients with severe neurological deficits find it difficult to sustain their optimism throughout the recovery journey. Depression can become an impediment to effective rehabilitation. Dipak is a wonderful example of resilience, optimism and unflagging belief in his ability to recover.”

Dr Monica Saini

Resident Physician
Neurology
National Neuroscience Institute



“If we stay strong and positive, we can fight anything. This is what I believe in and teach my children.”

Mdm Nai Poh Choo, 49

Homemaker

I knew I had a breast lump for some time. But I was busy looking after my family so I didn't see the doctor to get a check-up.

My oldest child has epilepsy and her seizures can get very bad. When she falls ill, she would be in and out of hospital frequently. I focused all my energy on taking care of her at home as I strongly believed that it was best for her to receive care in a familiar environment.

In doing so, I knew that I was stretching myself very thin as I always felt exhausted. Just before Chinese New Year in 2019, I collapsed at my workplace, a Japanese restaurant where I worked as a waitress.

When I woke up, I found myself warded at Changi General Hospital. After several tests, I was diagnosed with Stage 4 breast cancer which had spread to my liver.

Surgery was not an option since the cancer had spread to different parts of my body. I underwent intensive chemotherapy from March to August 2019. I am still on oral chemotherapy, but I know my time is limited.

Thankfully, my oldest child is in good health and working again. I have another daughter and son. Although my three children are all young adults, I really cannot bear to part with them.

I take pride in looking after my children. I try to live my life as normally as possible, cooking and cleaning the house even after my chemotherapy sessions. My children keep me motivated to continue fighting my cancer.

I am optimistic and cheerful by nature. I tell myself that there are others who are worse off than me – at least, I am not in pain. I do experience fainting spells but I choose not to dwell on my condition. If we stay strong and positive, we can fight anything. This is what I believe in and teach my children.

I had to quit my job because of my illness. I really miss working as I had such great camaraderie with my colleagues. With more time on my hands now, I go over to my aunt's home every day to help feed her ill husband while she is at work. I also help out at a temple, and share my homecooked food with needy elderly neighbours.

Sometimes, I buy food and milk powder for a baby whom I know is being neglected in my neighbourhood. I worry about what will happen to him when I am not around anymore.

My wish for the future is to live on a bit longer so that I can spend more time with my children. I also hope to continue helping others as it gives me great satisfaction to do what little I can for them.

“

Although Poh Choo has advanced cancer, she makes it a point to cheer up the patients she meets at chemotherapy sessions. She never fails to encourage them to stay strong and not give up.”

Susan Low

Community Assistant
Community Care
Changi General Hospital



“Even the simple act of getting out of bed each day can be hard for me, but I’ll keep fighting on. I will try every treatment I’m offered. Why give up when you are given the chance to live a little longer?”

Ms Abebi Chan, 21

(1999 - 2020)

When I was in my second year of polytechnic, I noticed a large lump in my abdomen. At my grandmother’s persistent request, I went for a check-up. My parents and I were shocked when tests revealed that I had Stage 4 Neuroblastoma. It’s a rare cancer that forms in certain types of nerve tissue, with a five-year survival rate of about 40 to 50 per cent.

Over the past two years, I have been receiving intensive treatment and have undergone almost every kind of treatment available – from surgery, chemotherapy to radiotherapy.

Treatment is painful, with numerous side effects. I am often in a bad mood because of the constant discomfort and pain, but I try really hard not to be overwhelmed by negativity.

Some days are harder than others. It was especially difficult last year when the doctor said that my cancer, which was under control for almost two years, had progressed. It felt like I was so near and yet so far from beating this cancer.

Through it all, I am very thankful for my medical team who have been very caring and attentive to my needs. I try to put on a smile whenever I step into the wards because I know that everyone is doing the best they can.

When I was undergoing treatment, I befriended another patient in the ward, a 15-year-old who is also fighting a difficult and aggressive cancer. Initially, he was quite uncooperative and did not want to take his medicine or allow the nurses to do any procedures on him. However, I managed to connect with him over a mobile game we both love to play. He then opened up to me and I reminded him that the nurses and doctors have our best interests at heart. I’m glad he has become more positive now, and also took my advice to cooperate with the medical team.

As an only child, I am very close to my mother. She accompanies me to doctor’s visits whenever she can, and cooks my favourite food so that I can eat after my treatments, which often make me lose my appetite.

For my 20th birthday last year, I was granted a wish by the Make-A-Wish Foundation Singapore. I requested to have a birthday celebration at a chalet. It meant a lot to me to be able to celebrate my birthday with my loved ones and the team of nurses and doctors who have been taking care of me.

A normal life is something I can only hope for, for now. Even the simple act of getting out of bed each day can be hard for me, but I’ll keep fighting on. I will try every treatment I’m offered. Why give up when you are given the chance to live a little longer?

“

Despite the poor prognosis and intensive treatments, Abebi was one of the most pleasant and lovely patients in the oncology ward. She always came to the hospital with a beautiful smile on her face for everyone she encountered. We can all learn from Abebi’s strength and positive attitude in life. Abebi truly inspired the people around her.”

Dr Soh Shui Yen

Head and Senior Consultant
Haematology / Oncology Service
Department of Paediatric Subspecialties
KK Women’s and Children’s Hospital

Ms Chan passed away on 2 October 2020. Her indomitable spirit remains an inspiration to all of us.



“I enjoy writing as it allows me to express my feelings and capture my thoughts. One day, I hope that my son will read my journals and understand my life journey.”

Ms Khusniwati Binti Md Mohani, 48

(1972 - 2020)

In 2014, I went for my regular health screening and received the devastating news that I had Stage 1 cervical cancer. A month later, I underwent surgery to remove my uterus, cervix, fallopian tubes, ovaries and lymph nodes. The physical pain was hard to bear and I mourned what I perceived was the loss of my womanhood.

I felt miserable, as if I had sunk into a dark hollow. I spent the next few days in deep reflection and prayer, and then made a conscious effort to snap out of the state I was in. Instead of dwelling on the negative, I decided to focus on the positive. I thanked God for giving me a son, who was five years old then, and counted the blessings I had received.

After the surgery, I underwent multiple sessions of chemotherapy and radiotherapy. The side effects drained me. I lost my appetite, threw up and suffered from diarrhoea. After 6 months of treatment, I eventually recovered. I found some contract work as a secretary and life went back to normal for a while.

Unfortunately, my cancer recurred two years later as Stage 4 cervical cancer. By July 2019, my kidneys had swelled in size. I had to have stents inserted to help to drain urine from the kidney and relied on a urine bag.

This time, I did not let this setback faze me. I reminded myself that I had overcome many other challenges before. Since young, I survived ordeals including suffering from scoliosis and surviving a fall into a monsoon drain. I also went through an abusive marriage and eventually, a divorce.

I draw strength from my religion, as well as the strong support from my friends and the National Cancer Centre Singapore. I also enjoy writing as it allows me to express my feelings and capture my thoughts. The nurses told me that I’m the only patient they know who sleeps with a notebook and a pen. One day, I hope that my son, who turns eleven this year, will read my journals and understand my life journey. For

his sake, I’ve done Advance Care Planning, appointed a custodian for him and written my will.

I hope my son will grow up to be a charismatic gentleman — one who is sincere, forgiving, generous and has a good heart. There should be no bitterness in his heart towards life, no matter what happens. I hope the same for myself too. This poem, which I penned in 2014, is based on my philosophy in life:

Untitled

Stomp, shall not
Shout, will not

But...
Thee call upon
The skies
The earth
Merge into one force
Within thee
Full feel
Full filled
Emerge new will
New inner strengths

To hold, if must
In patience, without bust
Vengeance, cast out
Victory, triumph in

The world is wide
The minds divide
Oneness or apart
Be true to one’s heart

HE is watching...

“

Despite her condition, Ms Khusniwati showed strong resilience and a positive attitude towards life. Her strong spirit inspires us to do our best for our patients.”

Li Ya Jie

Nurse Clinician
KK Women’s and Children’s Hospital

Ms Khusniwati passed away on 9 April 2020. Her indomitable spirit remains an inspiration to all of us.



“I can’t wait to get well so I can go back to school and be with my friends!”

Mr Raphael Lee, 12

Student

I’m 12 this year and I’ve been diagnosed with cancer four times.

I had my first brush with cancer when I was only eight months old. I can’t remember what happened then, but my parents told me there was a swell on my left forearm which turned out to be a tumour on the muscle tissue. I had to undergo an operation followed by chemotherapy and radiotherapy. I got better and my parents thought I would be fine after that.

But in 2016, doctors found that a secondary bone cancer had developed in my left forearm. I underwent cryotherapy and many rounds of chemotherapy. My eighth birthday was celebrated in the hospital. It was scary, but my parents were with me most of the time, so I was okay.

A year later, doctors found a tumour near my left wrist. This time, the doctors said they had to amputate my left arm as chemotherapy and cryotherapy may not be effective.

My parents were heartbroken by the news. My Dad explained to me why the doctors advised to remove my left arm. He wanted to let me decide as it was an important decision that would affect me greatly. I cried hard thinking about what would happen after the surgery but I decided to go with it.

I was really frightened before the surgery. I remember squeezing Mum’s hand tightly and screaming before the anaesthesia took effect. When I woke up, all the fear was gone. I smiled at my parents and nurses and waved my stump, joking that my left body felt lighter!

When I returned to school, I was given an award for being a “warrior”. The whole school cheered when I went on stage.

It came as a shock when I was diagnosed with bone cancer again in 2019. The doctor removed my right collar bone and one right rib, and I had to go for chemotherapy.

In 2020, I underwent a scheduled MRI and the results showed growths of nodules in my lungs. Again, I had to undergo surgery twice to remove the nodules.

Due to the cancer treatments, I could only attend one semester of school each year since Primary 2. I also lost the ability to hear high-pitched sounds due to chemotherapy. Nonetheless, I’m still determined to work hard for my Primary School Leaving Examinations this year and progress to secondary school.

Whenever I am hospitalised for chemotherapy, I would walk around the ward while pushing my IV infusion pump to visit my friends and quiz the nurses with riddles. When I see other kids in pain, I pray for them and hope they feel better soon.

Even though I lost an arm, I can do a lot of things by myself. I can help to hang the clothes and even sweep the floor or fry an egg! I enjoy science, crafts and drawing. Once, I drew pictures of the nurses who took care of me and made cards for them. This is to reciprocate their patience and professionalism towards caring for patients.

Sometimes I do cry because of my arm, but I know the treatments are important for me to recover. I can’t wait to get well so I can go back to school and be with my friends!

“

Despite his multiple cancer diagnoses and amputation, Raphael remains positive and does not give up hope. He is an inspiration to other patients and to his healthcare team.”

Yvonne Lim

Nurse Clinician
Haematology / Oncology Service
KK Women’s and Children’s Hospital



“Having battled with cancer for almost a decade, I have learnt not to dwell on the ‘what-ifs’, but to focus on the present.”

Ms Daphne Tan, 40

Corporate Banker

My mother passed away at the age of 25 due to breast cancer. I was only three years old then.

Growing up, the risk of breast cancer haunted me. I found lumps in my breasts and was no stranger to breast lump removal procedures. By the time I was a young adult, I had already gone through the procedure about 10 times. Although the lumps were always benign, I chose to remove them each time for a peace of mind. I took care of my health and went for annual medical check-ups faithfully.

Despite my best efforts, life dealt me with a hard blow in 2011. I was diagnosed with a brain tumour and had to undergo a 10-hour operation to remove it. Thankfully, the operation was a success.

But five years later, bad news hit again. During a routine scan, I was diagnosed with an early stage but aggressive breast cancer. My daughter was barely two years old then.

When the doctor broke the news, it didn't really come as a surprise. All I felt was sadness, and I wondered what would happen to my family if anything were to happen to me. I remembered what my father, who is my pillar of strength, always taught me since I was young – to have perseverance. I knew I could not give up on life, and decided to give myself the best chance of a complete recovery.

I completed surgery, chemotherapy and targeted therapy, and opted for a bilateral mastectomy even though it was deemed unnecessary at that stage. I just did not want history to repeat itself and risk having my daughter grow up without a mother.

At my doctor's advice, I also went for genetic testing and was found to have a rare genetic condition called Li-Fraumeni Syndrome. This meant that I am more likely to get breast, bone and soft tissue cancers. This vindicated my decision for a bilateral mastectomy.

Having battled with cancer for almost a decade, I have learnt not to dwell on the ‘what-ifs’, but to focus on the present. I am thankful that today, I have been given the all-clear from cancer and can return to work. I am also taking care of my father, who was diagnosed with lung cancer three years ago, but is responding well to treatment.

I recently bought an apartment, which will be ready in a few years' time. Hopefully my father will get better and can move into the new place with me. Most importantly, I hope to be present for all the different milestones of my daughter's life, now and in the future, and become what I envision a good mother would be.

It's important to share my story. By doing so, I hope to motivate others who are going through the same experience. My experiences have taught me to cherish life, and to always fight on even though the odds may be stacked against me.

“

Despite her health and personal setbacks, Daphne has a very positive outlook in life. Amid her busy schedule, she attends her numerous medical appointments, tests and treatments without fail. She also dedicates time to patient advocacy activities.”

Dr Kiley Loh

Consultant
Division of Medical Oncology
National Cancer Centre Singapore



“With the good friends I’ve made and the lives I’ve touched through volunteering, I feel that my life is more fulfilled than it was before my illness.”

Ms Florence Loh Suat Tin, 60

Retiree

Cancer treatment can be a difficult journey that’s painful and frightening. As a breast cancer survivor, I know how important it is for newly-diagnosed patients to have emotional support during the treatment process.

I was diagnosed with breast cancer in 2015. Although it is now in remission, the process of recovery was a painful one which involved surgery, chemotherapy and radiation therapy.

My two older sisters and their families took turns to care for me while my friends accompanied me for treatments. My Christian faith and church friends also offered me great comfort and encouragement, so I never felt alone in my journey.

Blessed with so much support, I wanted to pay it forward. I started volunteering with the Volunteer Engagement Team at the National Cancer Centre Singapore (NCCS) in 2017, where I’m also a member of the NCCS Breast Cancer Support Group. I help out with team activities, such as the Simple, Nutritional And Caring Kits (S.N.A.C.Ks) service, where volunteers serve drinks and snacks to patients undergoing chemotherapy at the NCCS Ambulatory Treatment Unit. I also chat with patients and lend them a listening ear.

I used to work as a church pastoral team member before I retired. My experience has helped me become more sensitive and attentive to the needs of others in the course of my volunteer work. I also share with other patients useful NCCS resources that they can tap on, or help direct them to relevant agencies for support.

But I didn’t want to stop there. I picked up knitting from a fellow volunteer so that I could contribute to the Knit for Hope programme. Words cannot describe the joy I get when I see my knitted hats bring a smile to a patient’s face.

Whenever patients ask me for advice, I encourage them to have a positive mindset and to empower themselves. This stemmed from a previous personal experience when I started losing my hair as a result of chemotherapy. It was the lowest point of my treatment journey, but I told myself to just deal with it – so, I went to the hair salon and had my head shaved. It was momentous as I felt that I took positive action and overcame a big hurdle.

With the good friends I’ve made and the lives I’ve touched through volunteering, I feel that my life is more fulfilled than it was before my illness. I am so thankful for the opportunities I have now, and I hope to learn more skills to continue helping others.

“

No task is too small for Florence, as long as it benefits other patients. Her ‘I-can-do-more’ spirit and ever-readiness to help out in volunteer programmes is an inspiration and keeps us driven in what we do.”

Delphine Huang

Executive
Division of Community Outreach & Philanthropy
National Cancer Centre Singapore



“I think of my cancer as a chronic condition, not a terminal illness. I do not let it dictate my lifestyle and I continue to live life to the fullest.”

Mdm Sally Kok Yuet Hoe, 58 (1961-2020)

In 2017, I had a persistent cough that lasted for a few months. I wasn't too worried but decided to see a specialist and go for tests just to be safe. Then the results came back — I had metastatic cancer that had spread from my pancreas to the lungs.

I will always remember the day I was diagnosed — 31 January 2018. The doctor told us that the cancer could not be operated on due to its advanced stage, and the expected survival rate for metastatic cancer patients was less than a year. I had a hard time coming to terms with the diagnosis and asked myself, “Why me?”

I had always lived a healthy lifestyle. At my job at the National Heart Centre Singapore (NHCS), I helped organise and participated in exercise programmes like Zumba and yoga regularly. I even participated in a charity relay run just two months before my cancer diagnosis.

However, I'm not unfamiliar with illness and death, having lost my mother to colon cancer and two sisters who passed away suddenly due to stroke. I prepared myself mentally for the challenges ahead. I chose to be thankful for the chance to receive treatment, and to have time to settle my affairs and be with my loved ones.

There have been many highs and lows during my battle with cancer over the past two years. In October 2019, my left lung collapsed and I required an oxygen concentrator 24/7 to breathe, but I told myself to look on the bright side and see the oxygen concentrator as my temporary aid. My highest point was when my cancer markers went down in end 2019, and I could make plans to travel with my family again.

Having worked at NHCS for the past 25 years, I understood the importance of taking charge of my health. For example, I understood the benefits of an intravenous (IV) port in cancer treatment, which allows access for drug infusion and blood taking, so I didn't hesitate when asked by my doctors to have it inserted. When other patients had questions about the IV port, I gladly

shared my experience with them. I also donated my blood and tissue to cancer research to help other patients in future.

The strong support and love from my family and friends helped me stay hopeful and positive. My husband and two sons never failed to make me feel loved and cherished. After my cancer diagnosis, my older son who was working in Denmark returned to Singapore to spend more time with me, and to care for me together with my husband. Meanwhile, my younger son got married in 2019 but he makes sure to visit me often. I also had great support from friends and colleagues at NHCS.

I think of my cancer as a chronic condition, not a terminal illness. I do not let it dictate my lifestyle and continue to live life to the fullest.

“

Despite her illness, Sally participated in a 3-km charity relay run and a yoga challenge in 2019. Her tenacity and faith have greatly encouraged her family, friends, medical team and fellow patients.”

Dr Choo Su Pin

Visiting Consultant
Medical Oncology Division
National Cancer Centre Singapore

Mdm Kok passed away on 19 April 2020. Her indomitable spirit remains an inspiration to all of us.



“Since young, my friends tell me I have this special power to turn things around. I believe it’s the power of the mind that helps me fight this disease.”

Mr Shawn Loh, 39

Businessman

I have been battling with brain and spinal cancer for more than 10 years. Even my doctor is amazed by my strong fighting spirit.

In 2009, I experienced a very bad headache and decided to have it checked. An MRI scan revealed a cancerous brain tumour sitting at the top of my spine. I underwent surgery to insert a shunt into my brain to relieve the pressure and completed a round of radiotherapy.

Things looked good for a few years but just before I reached the five-year mark in 2013, the cancer relapsed in my brain and spread to the rest of my spine. It was a huge blow as I was so close to being cancer-free. Since then, cancer has been an annual recurrence.

Over the past seven years, I underwent multiple rounds of radiotherapy and chemotherapy, including a high-dose chemotherapy in 2017 which was a highly risky treatment. I had very low immunity and stayed in an isolation ward for over a month. Unfortunately, even that was insufficient to wipe out the cancer.

Each time I’m told that my cancer has recurred, I would steel myself to face the treatment and tell myself that I would get well soon. Since young, my friends tell me that I have this special power to turn things around. I believe it’s the power of the mind that helps me fight this disease.

I am a cycling enthusiast. To me, fighting cancer is like riding a bike. Both are mentally and physically challenging, and require strong motivation to push through. My longest trip was a 320km ride in Hanoi in 2018, during the good months in between my treatments. As I cycled in the punishing and extreme weather conditions and tough hilly terrains, I pushed myself to press on, just like how I would motivate myself during treatments.

I’ve been a committee member of the Brain Tumour Society Singapore (BTSS) since 2014 and I help to raise funds for its activities. One of the signature events that I help to organise is the bi-annual Brainy Car Rally. I’m glad to be able to contribute by rallying my Lamborghini Club members to come together to ferry brain tumour kids around Singapore while raising funds for BTSS.

My wife is my pillar of support in this journey. We have been together since 2007 and got married in 2015. I’m also grateful to my oncologist Dr Tham Chee Kian, who’s been there for me throughout these seven years of treatment.

To me, the sky is the limit. I want to be happy every day, continue working and doing the things I like, and most importantly, spend more time with my wife and family.

“

Even though Shawn is battling a very challenging disease, he remains positive and continues to pursue his passions in life. His optimism and resilience show that one can live life to the fullest even when facing cancer.”

Dr Tham Chee Kian

Senior Consultant
Division of Medical Oncology
National Cancer Centre Singapore



“There are days when I feel depressed but I refuse to let myself stay down. I am a fighter – twice challenged but not defeated!”

Ms Sarah Low Kia Tian, 45

Homemaker

2010 should have been a happy year for me. I was expecting my second child and was looking forward to giving my young daughter a sibling.

But four months into the pregnancy, things started falling apart. I cannot really remember what happened, but my family told me that I suddenly became apathetic and unresponsive to my surroundings. I was not eating or drinking, and I slept a lot. There were days when I even forgot to go to work.

My parents had to take over caring for my four-year-old daughter. I vaguely remember my husband and parents scolding me and asking me what was going on. No one knew what was happening to me and little did they expect that I was severely ill. Eventually, I was in such a state of confusion and so weak that I could not even walk, and had to be sent to the hospital.

Tests showed that I had a malignant brain tumour (Glioblastoma Grade 4) that was affecting my brain functions. I needed immediate surgery but even that could not remove all the tumour and I had to undergo radiation therapy and chemotherapy. Worst of all, I had to terminate my pregnancy as the treatment would affect my unborn baby. It was the most heart-wrenching decision my husband and I had to make.

Even after surgery and treatment, my prognosis was bleak. I was given only a year to live. Amazingly, I survived against all odds. My fantastic family support and strong Christian faith were my lifelines, helping me to fight my cancer and overcome the grief of losing my baby.

However, life can be so unpredictable. Shortly after celebrating my sixth-year remission in 2016, I discovered a breast lump during a regular self-examination. I went for further checks and my worst fears were confirmed – I had breast cancer.

I could not believe that I had cancer again. I was devastated and cried buckets.

Once I got past the initial shock, I decided to take the bull by the horns. I chose to undergo bilateral mastectomy surgery and breast reconstruction. I also underwent chemotherapy again to wipe out the cancer.

I no longer ask, “Why me?”. I have accepted my condition and tell myself that cancer can be defeated. I try to stay positive so I can get better. I want to be able to take care of my family and honour God. Most importantly, I hope to be able to watch my daughter grow up.

There are days when I feel depressed but I refuse to let myself stay down. I am a fighter – twice challenged but not defeated!

“

I am deeply inspired by Ms Low’s positivity in life despite what she has gone through. She has shown great courage in dealing with her cancer diagnoses and treatment.”

Zhou Lifeng

Nurse Clinician
Neurosurgery
National Neuroscience Institute



“Looking back, what I managed to achieve through sheer effort and willpower during my rehabilitation journey was really not easy.”

Mdm Barbara Tan, 82

Retiree

I have Parkinson’s disease and am prone to falls. In November 2018, I had a bad fall that caused me to fracture my left hip.

I was in so much pain that I could not get up. As I live alone in a studio apartment, no one heard my calls for help. I ended up lying on the bathroom floor for almost two days. It was a very frightening experience.

Fortunately, my church friends who had come to take me out realised what happened to me, and got the police to break down my front door. I was sent to Tan Tock Seng Hospital and underwent a half hip replacement surgery.

I thought all would be fine after my surgery, but little did I expect the post-operative therapy to be so challenging and painful. At the Ren Ci@Ang Mo Kio nursing home, I was told that my rehabilitation could take up to six months. This made me worry about whether I would regain my mobility and independence.

At the nursing home, I fell into depression as I felt anxious about my future and found it difficult to adjust to the new environment. Fortunately, my strong Christian faith and caring church friends spurred me on. I made an effort to learn about my condition and how to get better through exercise and diet.

As I made progress with the help of my care team, I became even more motivated to work harder. On days when I had no physiotherapy sessions, I would do my ‘homework’. I practised walking and diligently did bed exercises to improve my range of movements.

I was so happy when my care team said that my strength had greatly improved after just a month, instead of the expected three months. After discussions with the care team, they revised my care plan to include more intensive therapy with the goal of allowing me to regain home independence in six months.

Looking back, what I managed to achieve through sheer effort and willpower during my rehabilitation journey was really not easy. The pain and discomfort of rehabilitation can deter one from keeping up with the exercises, but therapy is the only way to get better.

Although I still need to rely on a wheelie walker to move about, I am glad that I beat the odds and successfully regained my independence.

“

Barbara’s commitment and discipline to follow her care plan were astounding. The intensive therapy she underwent was no mean feat for someone her age.”

SivaKumar s/o Kala Muthu

Medical Social Worker
Ren Ci @ Ang Mo Kio (Nursing Home)



“I feared the worst but did not allow myself to wallow in self-pity. I wanted to get well, and was impatient to recover so that I could live life normally again.”

Mdm Hui Pui Pui, 85

Homemaker

As an 85-year-old, I thought I had seen much of life.

I grew up in Shanghai and experienced turbulent times as a child during the Sino-Japanese war and the 1949 Chinese Revolution. When I was barely 14, I moved to Hong Kong and embarked on a successful professional singing career, and was largely self-taught. At 18, I met my future husband, a Singaporean businessman. We decided to build our family in Singapore and I consequently gave up my professional singing career.

We had many good years together raising four wonderful children in Singapore. I am now enjoying my time with my six grandchildren and two great-grandchildren who live across three countries. I'm humbly blessed with a family of four generations!

But this was not all that life had in store for me. In June 2019, I suffered a serious stroke. I was unable to speak or eat well for almost three weeks, and lost mobility on my left side. I feared the worst but did not allow myself to wallow in self-pity. I was determined to get well, and was eager to recover so that I could live life normally again.

I was hospitalised for a week in Sengkang General Hospital, before being transferred to Sengkang Community Hospital for rehabilitation. I'm forever grateful to my family and most of all, the doctors, nurses and therapists, all to whom I owe my life. They gave me so much encouragement, support and care. I worked very hard during the physiotherapy sessions to regain strength and mobility. Thanks to them, I was able to speak and eat normally again after a few weeks.

While staying at the hospital, the doctors and nurses fondly called me “Po-Po” or grandmother. They were all very kind to me, and I would often share my life stories with them and encourage them to face obstacles bravely.

Whenever other patients in my ward needed help communicating with the healthcare staff, I would act as their interpreter since I am fluent in Mandarin and five different Chinese dialects. I enjoy helping others. With help from my children and grandchildren, I also brushed up on my English. These language skills enabled me to help other elderly patients who stayed in the same ward.

Since August 2019, I've been recuperating at home and still require some assistance to go about my daily life. Thrice a week, I undergo physio- and occupational therapy at St Luke's ElderCare. Although these 60 to 90-min sessions are physically tiring, I know they benefit me and are important for me to fully recover and regain my well-being again.

I'm very motivated to get better and stronger, and I'm so thankful and grateful for all the help and support provided by all the wonderful staff from the hospital and rehab centres. I really look forward to projecting my voice and singing my favourite songs for them again soon!

“

Mdm Hui's fighting spirit is amazing. Even though she is the patient, she motivates me to face challenges in life bravely. Her kindness and appreciation towards the rehabilitation team makes it such a joy to work with her.”

Javier Won

Dietitian
Sengkang Community Hospital



“The healthcare team had done their part in providing clinical care well, and I knew I needed to do my part at rehabilitation. After all, they can only do so much, and the rest is up to the patient.”

Mdm Sarah M Shakun, 61

Counsellor

For five years, I suffered from localised osteoarthritis in my left knee. I endured the pain and tried different treatments but to no avail. When I was subsequently told to undergo knee surgery, I was afraid I would lose my mobility as I am a very active person who enjoys cycling, walking and working out. I am also on the go a lot for work, teaching and counselling at various locations.

Despite my fear, I knew I had to treat the pain. My doctor at Sengkang General Hospital assured me that I would be able to walk again shortly after surgery. It was a personal achievement when I eventually decided to go for the surgery in March 2019.

The surgery was successful, but the road to recovery was challenging. As a church counsellor, I always try to be optimistic and practical, and I carried this same mindset with me when I was transferred to the Sengkang Community Hospital (SKCH) for rehabilitation. The physiotherapists and dietitians there were warm and engaging, and I learned as much as I could from them on the recommended exercises and diets so that I could recover quickly.

It was difficult to stand and walk due to the pain. The initial period was especially difficult but when I managed to take my first few steps, I was motivated to do more and get well fully.

Looking back, I attribute my smooth recovery journey to two key factors – having a positive mindset and trusting the healthcare team, including taking their advice and following through with it. It is a misconception that a patient’s recovery relies solely on the healthcare team. For me, I saw that the healthcare team had done their part in caring well for me, and I knew I needed to do my part at rehabilitation to speed up my recovery. After all, they can only do so much, and the rest is up to me.

Being naturally bubbly and outgoing, I sometimes go around the rehabilitation ward to cheer other patients on. The healthcare team told me that my enthusiasm influenced some patients in my ward to work harder at their rehabilitation, and I am glad I had a positive effect on others!

I believe healing starts from within – keeping a positive mind generates affirmative energy, which radiates outwards and helps with physical healing. On the contrary, fear, stress and worry breeds negativity and can derail the progress of recovery. I am grateful to have a caring family and my strong Christian faith to help me overcome my health challenges. I hope to be able to do more to help people in need.

In September 2019, I had to undergo another surgery on my right knee. But it was an easy decision to make after making a smooth recovery from the surgery on my left knee. I am very thankful to be mobile and pain-free now!

“

It was a joy having Sarah at SKCH. She was enthusiastic in learning from the dietitians and physiotherapists on nutrition and exercise.”

Javier Won

Dietitian
Sengkang Community Hospital



“It brings me joy to be able to help other patients by sharing my experiences. I am, in turn, motivated and inspired by their courage and determination to get well.”

Mrs Wendy Tan-Kuah, 60

Retiree

There have been a couple of phone calls I received that have changed my life completely. One kickstarted my education consultancy business which I have run since 1981; the other saved my life.

In 2014, a former client called to share with me that his wife had passed away just three months after she was diagnosed with ovarian cancer. Out of concern, he suggested that I go for cancer screening too. Although I was feeling fine and didn't seem to have any symptoms, I heeded his advice.

To my shock, I was diagnosed with uterine leiomyosarcoma, a rare type of cancer that affects the smooth muscle tissue. I had a full hysterectomy to remove all the female organs as well as the 5.5 cm tumour near my left ovary. Further investigation and a PET scan confirmed it was Stage 4 cancer and had spread to other parts of my body. After the surgery, I took a wait-and-see approach towards further treatment as chemotherapy was not known to be effective for my type of cancer.

That diagnosis was a wake-up call for me. Not wanting to waste any time, I went on 14 holidays in a year, travelling to places I had always wanted to visit but never found time for, such as Bali, Japan, Greece and Paris. This would have been impossible before as I spent most of my time working.

Today, I am no longer the workaholic I used to be. I leave my business to my “Three Musketeers” to run – my husband and two sons. My sons take care of me very well at home, with my older son managing all the housework. My three siblings and elderly mother have also been very supportive. I have learnt not to harp on things or worry too much, but just be thankful for the simple pleasures in life, such as spending time with my loved ones.

I wanted to reach out to other cancer patients to spread the love and blessings I've received. In 2016, when I knew that KK Women's and Children's Hospital, National Cancer Centre Singapore and National University Cancer Institute Singapore were setting up the Sarcoma Support Group, I volunteered to lead the group. It brings me joy to be able to help other patients by sharing my experiences. I am, in turn, motivated and inspired by their courage and determination to get well.

Our support group reaches out to patients and their caregivers to provide emotional support. Members share knowledge and personal experience to help those who have difficulty coping with their cancer diagnosis and treatment. We also organise regular educational talks and activities such as nature walks, line dancing, yoga, and art and craft sessions for patients and their families.

In 2017, I found out that my cancer had spread and the tumour is inoperable due to its location. It has been about three years since, and I'm thankful for each day I wake up to. I continue to live a healthy lifestyle by practising yoga and brisk walking every day. My strong Buddhist faith gives me strength to keep going, and I look forward to more travelling for as long as I am able to.

“

Although Wendy has advanced stage cancer, she dedicates her time to supporting others who are sick. To me, she embodies indefatigable strength and courage.”

Ann Kuo

Principal Occupational Therapist
Singapore Cancer Society



“I would be lying if I said I wasn’t devastated. However, having a positive mindset is important and I always remind myself to be patient and diligent. I tell myself that any improvement, big or small, makes a difference as I work towards a full recovery.”

Mr Herman Ho, 39

IT Specialist

My wife and I are from Belitung, Indonesia. We moved to Singapore in 2008 and have two daughters, aged 13 and 10. I worked as an IT specialist and enjoyed my job very much. Life was simple but we were happy. However, everything changed after that fateful day, 15 March 2019.

My wife was flying to Belitung to visit her family that day. Although I had a bad headache, I insisted on sending her to the airport. I took some painkillers and thought the headache would go away, but it persisted over the weekend. On Sunday afternoon, I took a nap and tried to sleep it off.

When I woke up, I found myself in Singapore General Hospital (SGH) with no recollection of what happened. I was told I had a stroke and had been in an induced coma for eight days after doctors removed a part of my skull to release the built-up pressure in my brain.

As a result of the stroke, part of my brain structure was damaged. I developed aphasia, a language impairment condition resulting from the injury to my brain. I could not express myself, understand others or write properly. It was a big blow to me as I could previously speak English, Mandarin, Bahasa Indonesia, Hakka, Teochew and Cantonese fluently.

Following a three-week stay in SGH, I underwent rehabilitation in Bright Vision Hospital for a month to re-learn how to communicate. The recovery journey was arduous, and I was frustrated and constantly moody.

Despite this, my family was very understanding and motivated me to get well. I worked hard at speech therapy and started participating in Chit Chat Café, a support network for people with aphasia. Things started to improve and I was also in better spirits. By October 2019, I returned to work on a part-time basis.

The same month, I underwent a cranioplasty, a surgery to replace the missing portion of my skull. This meant I would no longer have to wear a protective helmet and could look like my old self again. I was also excited at the prospect of returning to work full-time.

Sadly, complications arose a few weeks after my cranioplasty and I had to remove the replacement skull. My doctors are still assessing my condition before they can reschedule me for another cranioplasty.

I would be lying if I said I wasn’t devastated. However, I’m grateful to have a supportive family and friends and for them, I cannot and will not give up. I share my experiences with friends at Chit Chat Café because the mutual support is what keeps positivity flowing and I hope they won’t give up too.

“

Herman makes the effort to befriend others with aphasia. He often shares positive messages to encourage and motivate fellow patients, inspiring them to persevere onwards in their journey to recovery.”

Cheryl Lee

Speech Therapist
Singapore General Hospital



“In life, you lose some and gain some. I feel like I’ve lost more than I’ve gained, but I am never giving up. There are so many more things I want to do and I know I can achieve them.”

Mr Melvin Ong, 29

Musician

I used to be an extremely negative person. Before the accident, I was living out my passion for music as the vocalist and bassist of a metal band, and I travelled extensively for performances. But I hated my life and had thoughts of ending it all on a few occasions.

The accident happened on 21 July 2019. I slipped and fell off a two-metre-high platform, and the fall crushed my upper spinal cord.

When I regained consciousness, I found myself in the Intensive Care Unit at the Singapore General Hospital (SGH). The fall had caused me to be immobile from the shoulders down. In a span of a few weeks, my heart stopped four times. Each time, I was resuscitated. My family was relieved, but I was miserable to be alive.

Everyone showered me with support and encouragement, but their words barely penetrated through the medical drowsiness and emotional pain I experienced. I had frequent outbursts of anger and was extremely difficult towards everyone.

It was my elder brother who stopped me from wallowing in self-pity. He said, “There are people out there battling critical illnesses, and they are still giving their best. You have been given four chances at life. Why not give it another shot?”

I spent exactly 100 days in the hospital. The medical team was pivotal in my road to recovery, both physically and emotionally. Beyond taking care of me, many of them visited me outside of their work and checked in on me regularly, even till today. It’s amazing how they can care so much for someone they barely know.

My family and friends also gave me overwhelming support. I even received messages of support from people whom I met only once during my band tours.

With such love and support, I found the inner strength to pick myself up. I worked on breathing exercises diligently and when I left the hospital, I could breathe independently without the ventilator for hours, and eat and drink normally.

Today, I’m no longer the negative person I was before the accident. I stay positive and keep myself busy, even though I am unable to move on my own. It is still tough, but I have faith that I will lead a normal life eventually.

I’m writing a book to document my journey to motivate others who are facing similar challenges to live life bravely and with gratitude. I can’t physically type, but with the help of technology, I can do so with a software using my eyes. I hope to publish the book this year and channel part of the proceeds to a good cause.

In life, you lose some and gain some. I feel like I’ve lost more than I’ve gained, but I am never giving up. There are so many more things I want to do and I know I can achieve them.

“

Melvin has shown me how much we can achieve just by putting our minds to it. He always shares his recovery goals, and seeing him tick them off his list is truly inspiring.”

Mardhiyah Binte Mohamed Anwar

Senior Staff Nurse
Surgical ICU
Singapore General Hospital



“One day, I hope to work in the medical field to develop innovative medical devices that will benefit patients living with stomas.”

Mr Ui Wun Juan, 21
Full-time National Serviceman

I was diagnosed with Crohn’s Disease, an inflammatory bowel disease, when I was 13. It started with diarrhoea more than five times a day, and progressed to vomiting and abdominal pain. I lost about three kilograms within a month.

Medication helped to reduce the symptoms but I had a serious flare-up when I was 14. I was running to the toilet frequently and lost so much blood through my stools that I needed a blood transfusion. My intestine was swollen with ulcers and the pain was unbearable. My father was initially hesitant when doctors recommended for me to undergo surgery, but seeing that my condition was worsening, he eventually decided that it was the best option.

Before the surgery, the doctor told me that a section of my small intestine would be removed and that I would have a stoma (an opening on my abdomen that is connected to the digestive system to allow for waste discharge) and a stoma bag. I remember how shocked and depressed I was when I saw the stoma bag after my surgery. I was unsure if I could cope with it at school, and continue playing my favourite sports like basketball and running. But with the healthcare team’s encouragement and guidance, I adjusted to life with a stoma bag.

Due to the surgery, I missed four months of school during Secondary Three. It affected my studies and I almost couldn’t progress to Secondary Four that year. Thankfully, with the help of my classmates and teachers, I managed to pass my ‘O’ levels. In 2016, I had the option to undergo surgery to close the stoma before I started my polytechnic studies, but I decided to postpone it until I completed my diploma. It was a difficult decision as I had been looking forward to removing the stoma, but I was determined not to miss any moment of my school life again.

There are some inconveniences living with a stoma bag. I cannot swim and must be careful with strenuous

activities as excessive perspiration may cause the bag to come off. Leakage of the stoma bag is a constant worry for me. I also had to learn to empty the bag whenever it is full and change the bag every three to five days.

Having lived with the stoma bag for the past eight years, I have grown accustomed to these inconveniences and learnt to live a normal life as much as possible. Recently, I started running and picked up basketball again. I even took part in the five-kilometre Colour Run last year and joined camps in polytechnic.

I like meeting new people, and I’m always happy to share my experience with young patients in the same situation. I try my best to clear their doubts and assure them that it is possible to live a normal life with a stoma. By the end of this year, I will be removing the stoma before I start school at Nanyang Technological University. One day, I hope to work in the medical field to develop innovative medical devices that will benefit patients living with stomas.

“

Despite having a stoma since he was 15, Wun Juan leads a positive and active life like a normal youth, coping with his school work, examinations and Co-Curricular Activities. His courage and determination are admirable.”

Loy Kia Lan

Senior Nurse Clinician (Advanced Practice Nurse)
Singapore General Hospital



“As a compulsive optimist, I believe everything happened for a good reason. I was determined to get well.”

Mrs Viji Ramakrishnan, 51

Homemaker

I was born in Bangalore, South India. Growing up, I was extroverted, active and healthy. I enjoyed sports and was also a trained classical singer. At the age of 23, I moved to Singapore with my husband. We were happy to settle down here and welcomed our only child in 2000.

My nightmare started a year and a half later. One day, I developed a high fever and an ear infection that wouldn't go away. Shortly after, I twisted my ankle which became severely swollen and didn't heal.

Seeing that I wasn't responding well to medication and was losing my appetite, the GP suggested I do a blood test. My mind went blank when she told me I had leukaemia and required immediate hospitalisation.

I was admitted to Singapore General Hospital (SGH) on 15 May 2002. In less than 24 hours, I was put on intravenous chemotherapy treatment.

Initially, I was in denial and thought there was a misdiagnosis. I eventually came to terms with my condition and as a compulsive optimist, I believed everything happened for a good reason. I was determined to get well.

In October 2002, I underwent a stem cell transplant to stimulate new and healthy bone marrow growth in my body. By then, I had been in the isolation ward for many months and lost 15kg. I was so relieved that the transplant was successful and I was discharged shortly after.

Little did I expect that the days following would be the hardest. I couldn't cope with the demands of daily life and fell into severe depression. I cried all the time and had frequent outbursts of anger. My family walked on eggshells around me and friends distanced themselves.

The internet was still in its infancy back then, so I turned to self-help books, exercise, prayer and meditation in hopes of curbing my anger. I desperately wanted to speak with someone who could help me make sense of what I was going through. This went on for a few years.

In 2008, I decided to volunteer at SGH to meet other cancer patients who needed emotional support. I even enrolled in a conversational Mandarin class so I could converse with more patients. In the process of sharing my cancer experience, I realised I was also healing emotionally. It took me nearly six years to finally come out of my depression.

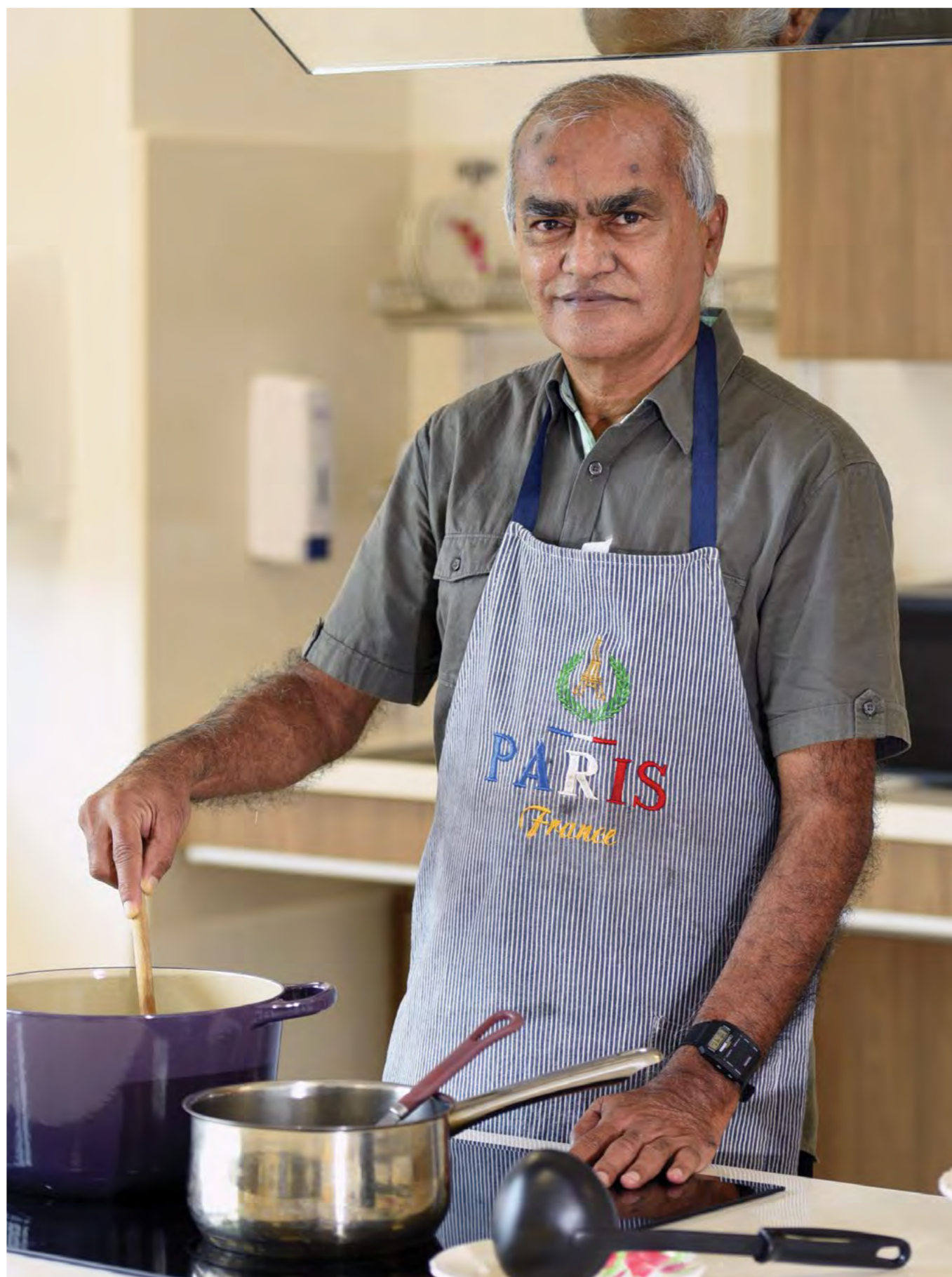
Looking back, I am thankful to be able to watch my daughter grow up, and for the opportunity to help others. Once, I was at the hospital when a Chinese lady approached me to express her gratitude for the time I held her hand and quietly comforted her when she was starting her first chemotherapy treatment. Such experiences keep me going. They remind me that I have a difference in someone's life, and I hope to continue doing so.

“

Mrs Viji faced her illness with grit and grace. She was never bitter about her diagnosis and always stood out in the ward with her bright smile. Her persistence to help others has encouraged other like-minded patients to come forward as well.”

Tan Chor Kien

Senior Nurse Clinician
Singapore General Hospital



“I decided to get out of the house and continue with my life. When we stay home worrying, there is a tendency to focus on what we cannot do, instead of what we can do.”

Mr Chandra Mohan s/o Narayanasamy, 68

Retiree

I used to work in finance and administration. I enjoyed working with numbers, and would spend long hours on the computer.

All that slowly changed when my vision started declining after I was diagnosed with diabetes in 2000, and subsequently diabetic retinopathy in 2006. In 2013, my vision deteriorated so much I could no longer work and had to retire at the age of 61.

By 2015, my vision became even more blurred due to Age-Related Macular Degeneration. I was told by my doctor at Singapore National Eye Centre (SNEC) that I might eventually lose my sight.

Around the same time, my wife passed away from cancer. Hit with one devastating news after another, I felt lost and afraid. I even had suicidal thoughts as I was very worried about turning blind. Although I have three children, they have their own lives and I did not want to burden them.

Thankfully, I received counselling at SNEC and was referred to the Singapore Association of the Visually Handicapped (SAVH). There, I underwent mobility training on how to use the white cane and learnt basic skills such as simple cooking and doing housework with limited vision.

At SAVH, I met many visually impaired people who lead independent lives despite having conditions that are more serious than mine. This motivated me greatly to live my life to the fullest.

I decided to get out of the house and continue with my life. When we stay home worrying, there is a tendency to focus on what we cannot do, instead of what we can do.

Since joining SAVH, I have been participating in its White Cane Club activities like visiting Gardens by the Bay and going on day trips to Malacca. I have even taken part in sports that I've never tried before, such as dragon boat and bowling!

Every Saturday morning, I participate in RUNNINGHOUR, a running club that promotes integration of people with special needs. At the weekly running sessions which are held at different venues such as Bishan Park and Bedok Reservoir, I get paired with volunteers who are my running guides. I enjoy the exercise as well as the interactions with other participants and volunteers very much.

Through these activities, my network of friends has grown. I used to be more quiet and reserved, but now I make friends easily and enjoy sharing my experiences with other patients.

Even though I was diagnosed with glaucoma in 2019 and my vision is further deteriorating, I am now more confident about living with blindness than before. I will continue to try new experiences. In fact, I'm looking forward to taking Mandarin lessons later this year. I also hope to pick up new skills so that I can find a job in telemarketing.

“

Chandra has come a long way from his initial dejection over his visual impairment. His determination to stay independent is impressive.”

Linda Chan

Executive
Office of Patient Experience
Singapore National Eye Centre



“With all that has happened, it is sometimes not easy to see the silver lining. But I still choose to count my blessings. It helps me stay positive throughout my illness, and keeps the smile on my face!”

Mdm S. Sathamba, 72

Retiree

It took me a while to accept my condition but I'm now able to smile from the heart, especially when I see the love from all the people who care for me. I feel really blessed to have a dedicated elder sister in Supama, a loving husband and son, a capable and kind helper, as well as compassionate doctors and nurses who have cared for me over the years. Although I still feel down on some days when I think of the past, I am mostly content and grateful now.

When I was younger, I was very independent and derived great joy from caring for my family while running my provision shop with my husband.

I was diagnosed with liver problems in my 60s, but I could still take care of myself and my medical appointments without relying on anyone. But when I first found myself walking slower than I usually would, I started to get worried.

My fears were confirmed after I woke up from a fall two years ago. I fell unconscious after I hit my head in my bedroom, and was sent to the hospital. When I finally managed to get back on my feet, I felt so different and helpless. Everything felt terribly confusing. Soon after, I was diagnosed with vascular Parkinsonism at the age of 71.

Over time, the fear and confusion lessened as I tried to stay positive. I always try to keep a smile on my face, even though it gets frustrating when I am unable to do things I enjoy, like meeting my friends, going to the market or cooking a meal for my family.

I am very thankful that Supama is always around to take care of me. I used to be the one doing the cooking at home, but my sister now cooks for me and my family. Watching her cook the familiar dishes I used to make brings me comfort.

It would be a lie to say that I don't miss my life before it was drastically changed by my illness. But my sister often reminds me to be grateful for what I have. She tells me that being in a wheelchair is a normal part of ageing, and that there are others in a similar position as me, while some are even worse off.

With all that has happened, it is sometimes not easy to see the silver lining. But I still choose to count my blessings. Taking stock of what I have rather than what I can no longer do helps me stay positive throughout my illness, and keeps the smile on my face!

“

Sathamba used to take care of her elder sister when they were younger but in a reversal of roles, she has become the one who needs her sister to care for her. While many may dwell on the negatives, Sathamba is a joyful person who smiles often and displays great inner strength.”

Dr Meykkumar s/o Meyappan

Family Physician
SingHealth Polyclinics – Pasir Ris

Mdm S. Sathamba's sister, Mdm S. Supama, is a winner of the Inspirational Patient & Caregiver Awards 2020 — Caregiver Category. Her story is on page 83.



“Having grown up in a ‘kampung’, Sunlove Home reminds me of the community spirit of the old days. I enjoy meeting other old folks there and helping them in ways I can.”

Mr Ang Kim Axe, 63

Retiree

I was diagnosed with Alzheimer’s Disease in 2013, when I was 56 years old. It started off with sleep difficulties and random mood changes. My wife and two daughters sensed that something was not right, and took me to see a doctor when I started talking and laughing to myself.

After my diagnosis, I had to stop working because I could not do the usual things I used to do. This hit me hard as I was the sole breadwinner of the family and had been working as a lorry driver for more than 40 years since I completed primary school education. I used to work six days a week and was seldom at home, so it was not easy for me to adjust to a new lifestyle. As my symptoms got worse, there were changes in my behaviour and there was a decrease in my concentration. My memory also deteriorated and I was not able to recognise the people around me. I had to rely on my wife to help remind me.

With support and encouragement from my family, I started attending Sunlove Dementia Day Care Centre in Ang Mo Kio in 2016 and was engaged in many cognitive and therapeutic activities by the friendly staff. Things got better and I made many friends, most of whom I can remember by name. We are like a big family where we know one another.

I enjoy taking part in the centre’s activities, such as singing, gardening and basketball. I also get to learn new things, such as recreational mahjong which I picked up by observing my friends play over a few months. The staff were really surprised when they saw me sitting at the mahjong table for the first time! Sometimes, newcomers to the centre get upset and have emotional meltdowns. I try to calm them down by conversing with them in their dialect and reassuring them.

I started out by visiting the centre twice a week, but I enjoyed the activities so much that I now go there four times a week. Having grown up in a ‘kampung’, Sunlove Dementia Day Care Centre reminds me of the community spirit of the old days. I enjoy meeting other old folks there and helping them in ways I can. On the days that I’m not at Sunlove, I visit the Residents’ Committee (RC) centre near my home. Interacting with other people and helping out at the RC helps me stay active and alert, which is good for my condition.

I don’t ask for much out of life. My only wish is to be healthy so I can see my daughters get married and be able to continue doing the things I enjoy.

“

Mr Ang is always calm, composed and very helpful towards others. He actively participates in all our programmes and encourages others to do the same. He is very self-motivated and shows keen interest in completing all his given tasks.”

Guna D

Assistant Director of Nursing
Sunlove Dementia Day Care Centre – Ang Mo Kio



“Working and interacting with people have made me much happier. I like experiencing new things and it feels good knowing that I have a role to play in the world.”

Mr Cheong Leong Ching, 62

Healthcare Assistant

I was diagnosed with schizophrenia in my 30s. I had to quit my job as an assistant at a provision shop as I was afraid to meet people, especially strangers. My mother took care of me, and I stayed at home without any hope for the future. As it was difficult for my family to manage my condition, I was admitted to the Institute for Mental Health (IMH) and later referred to Sunlove Home in 2001.

Staying at Sunlove Home turned my life around. I was surrounded by warm and helpful staff and residents. We chatted, enjoyed music together and went out for meals occasionally. I gradually started to open up and felt more comfortable sharing my feelings and experiences with others. Even though it hurt to bring up painful memories, I learned to trust my new friends, and it felt good releasing the emotions that I bottled up over the years.

With help from the staff at Sunlove Home, my condition improved. In 2013, I found a job as a housekeeper at Changi General Hospital (CGH). It was hard for me at first, as I had not worked for more than 20 years. I was nervous about leaving the house and venturing into a ‘new world’. Fortunately, the friendly staff and patients at CGH put me at ease.

Working life changed the way I perceived my environment and people around me. I used to view others with suspicion. Now, I feel encouraged by the friendliness of the people I meet at work and in public places.

After I started working, I also realised how hard it must have been for my mother, who had to work while taking care of me. She had a tough life raising five children. I began to appreciate all she has done for me and I visit her whenever I am able to take leave from work.

In 2019, I switched to working at one of Sunlove’s senior activity centres. Every morning, I would head out before the sun rises to take a bus to my workplace and return only late at night. I help to keep the centre clean and comfortable for the seniors. The best part of my job is that I also get to interact, and exchange experiences and stories with them.

I hope to be able to work at the senior activity centre for as long as I can. Working and interacting with people have made me much happier. I like experiencing new things and it feels good knowing that I have a role to play in the world.

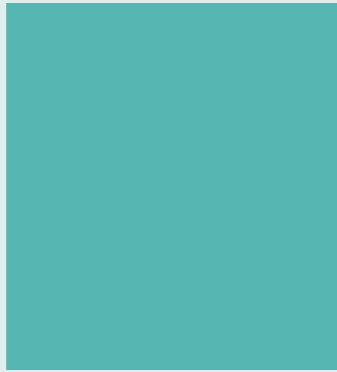
Previously, I lost hope and could not see any future for myself. With the help I received at Sunlove Home and the support from my family, I have become more confident. I want to do my best to help others, just as how others have helped me before. I want to make more people smile.

“

Despite suffering from schizophrenia since his 30s, Mr Cheong has made good progress and has been working for the past seven years. He is testament to the fact that with sheer determination and grit, patients with mental health issues can still contribute to the community. His positive spirit is a great inspiration to both the staff and residents at Sunlove Home.”

Guna D

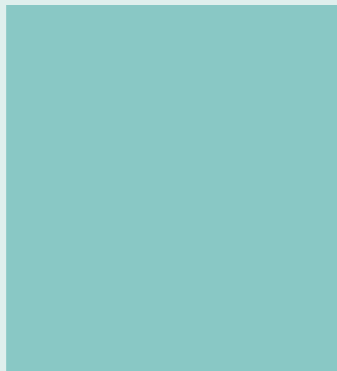
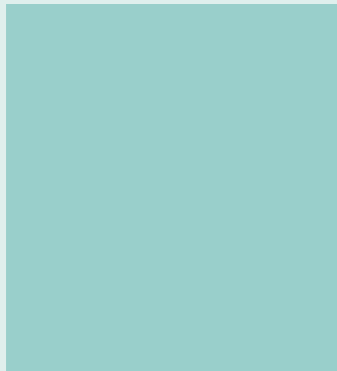
Assistant Director of Nursing
Sunlove Home



INSPIRATIONAL CAREGIVERS

PARTNER-IN-CARE AWARD

Mr & Mrs Tee Meng Kem



Ms Siti Nur Arina Bte Abdul Rahman & Ms Siti Nur Ariani Bte Abdul Rahman

Mdm Liaw Soon Fong

Mdm Juliah Bte Kasiman

Ms Toh Shiling

Mdm Nagajothi Marimuthu

Mr Nicholas Sim

Mr Ng Buan Hian

Mr Riechard Ang

Ms Amanda Pang

Ms Elaine Chiang

Mrs Wong Lee Yong

Mdm S. Supama

Mdm Farah Juwita Bte Alias

Mdm Seah Shiang Ping

Mr Tan Shew Sia

Ms Nur Azizah Bte Abdul Malik





“We often tell this to parents who feel lost because of their child’s illness: Be strong for your child, because he looks up to you as his role model.”

Mr Tee Meng Kem, 49
Engineer

Mdm Irene Goh, 50
General Manager

Our daughter, Yu Tong, was diagnosed with type 1 diabetes when she was only two and a half years old. When we first learnt of her condition, we were so affected that we could not focus on work and had to take an extended break to process our feelings. It took us three months to finally come to terms with it.

The turning point came when we joined a camp organised by the Diabetes Support Group and Sugar Rush Teen Support Group for young patients at KK Women’s and Children’s Hospital (KKH). We saw how children with diabetes could lead happy and normal lives. That gave us hope that Yu Tong, too, could live her life to the fullest despite her condition.

Caring for a toddler with diabetes was challenging. We picked up caregiving skills from the nurses at KKH and gradually became confident at managing Yu Tong’s diet, finger pricks for blood glucose tests and insulin injections. Thankfully, Yu Tong seldom cried or fussed. Seeing how brave she was despite her tender age inspired us to stay strong.

We didn’t want her to feel left out from school activities or the need to hide her condition. We would plan ahead and prepare her for major changes and events, such as starting primary school or overseas school trips.

As Yu Tong grew older, we taught her to manage her diabetes more independently. We did research to find the best devices, such as a wearable blood glucose sensor and insulin pump which she could handle easily on her own. We tried them on ourselves first to ensure that they were safe and effective for her.

Today, Yu Tong is a cheerful and optimistic 17-year-old who manages her own diet, blood glucose sensor and insulin pump. She is also a volunteer with Sugar Rush where she shares her experience and helps younger patients.

Through our caregiving journey, we understand the importance of supporting parents of newly-diagnosed children who face similar challenges as we did. We often share our experience to motivate and reassure them.

Together with the KKH team and other members in Sugar Rush, we worked to improve support for parents and children, such as initiating a Mummies chat group to share useful tips and encouragement to support one another. We also came up with a standardised letter for parents to inform the school of their child’s diabetes, so that teachers know what to expect and take note of.

Caring for Yu Tong has taught us more about ourselves and challenged us to broaden our perspectives. We often tell this to parents who feel lost because of their child’s illness: “Be strong for your child, because he looks up to you as his role model.”

“

Mr and Mrs Tee have generously given their time and support to patients, their families and the KKH diabetes care team for nearly 15 years. Thank you for partnering us!”

Lim Pei Kwee

Nurse Clinician
KK Women’s and Children’s Hospital



“Sometimes, we wonder if these illnesses are a blessing in disguise since they forced our parents to stop working. Prior to this, they worked so hard for the family. Now, it’s time for them to put all that aside and have a good rest at home.”

Ms Siti Nur Arina
Bte Abdul Rahman, 25
F&B Assistant

Ms Siti Nur Ariani
Bte Abdul Rahman, 24
F&B Assistant

For as long as we can remember, our parents have been unwell. They battled with diabetes while we were growing up, and suffered other illnesses as the years went by.

When our mother was still mobile, she would sell home-cooked food to supplement our family’s income. The shops in our neighbourhood were stocked with her delicious kueh, and she sometimes even catered meals for our school.

However, when we were in secondary school, she was diagnosed with chronic kidney disease and needed dialysis three times a week. One thing led to another – she suffered a stroke in 2013 and eventually had to have both her feet amputated due to diabetes.

Our father was a very hardworking man who held many jobs to put bread on the table for the family. But he suffered a stroke in 2010 and had to stop working. He is now undergoing rehabilitation to regain his mobility.

With both parents reliant on us for their daily care, our life pretty much revolved around them – administering medications, accompanying them for medical appointments and doing the household chores, all while juggling school. It never really struck us that our lives were that much different from others, or that we were doing any more than our peers. Perhaps it was also because we were fortunate to have cousins and relatives who would help care for our parents while we were at school.

We are now working at the same company, and our employer is understanding of our situation. We are allowed to work in shifts that do not overlap so that we can take turns to care for our parents.

While we do have concerns about the future, we try not to dwell on them and focus on the positive. For example, the fact that we are currently able to manage work and care arrangements for our parents is a great blessing. Most importantly, we have each other and can face whatever lies ahead together. We believe there is a reason for everything, and that the path will eventually smoothen out in the future.

Sometimes, we wonder if these illnesses are a blessing in disguise since they forced our parents to stop working. Prior to this, they worked so hard for the family. Now, it’s time for them to put all that aside and have a good rest at home.

“

Since their school days, Arina and Ariani had to grow up quickly to cope with their family situation. Now, they both work part-time to support their family. Through it all, they did not complain or indulge in self-pity about their circumstances, but stayed positive and continued to care tirelessly for their parents. Their devotion towards their parents and filial piety are an inspiration.”

G Poongkothai

Community Assistant
Community Care
Changi General Hospital



“My advice to other caregivers is not to give up hope. A caregiver can make a lot of difference to the patient. Adopt a positive attitude and just do the best you can.”

Mdm Liaw Soon Fong, 61

Retiree

My husband, Dennis, used to work as a taxi driver while I was a clerk at my father's shop. We led a simple and happy life.

Our lives changed after Dennis had a cardiac arrest and collapsed at Bedok Town Centre in July 2014. He was 56. Bystanders tried to help him but by the time he was sent to Changi General Hospital (CGH), he was clinically dead — his heart had stopped and he had stopped breathing for over a minute. Thankfully, doctors managed to resuscitate him but his prognosis was poor. They told me that even if he survived, he might remain in a vegetative state and require full-time nursing care.

Things were indeed bad after he awoke from a week-long coma. He lost all his cognitive functions, and was unable to speak or understand the simplest concepts. He was also restless with immobility on one side. As we have no children, I was his sole caregiver and left my job to look after him.

Three months after undergoing surgery and rehabilitation at CGH and St. Andrew's Community Hospital, Dennis remained wheelchair-bound, unable to speak or perform basic tasks. Despite this, I grew to understand his needs from the time I spent caring for him. I strongly believed he would get better.

Back home, I kept up with the physio- and occupational therapy exercises that we learned from his healthcare team. I also tried alternative methods, such as acupuncture and massage.

To stimulate Dennis cognitively, I helped him relearn alphabets and numbers, read and explained bible passages to him daily and brought him to familiar places to help regain his memory.

I gradually saw signs that he could vaguely understand me. He could remember more things and started to communicate with me through sounds. As he regained more functions, I enrolled him in support group activities and community exercises so he could socialise and get more physical and cognitive stimulations.

I recall the first time Dennis leaned his head towards the buzzing washing machine and tried to help me hand-wash the laundry. That was a major milestone since his diagnosis with Hypoxic Ischemic Encephalopathy and stroke. These may seem like simple tasks, but they require extensive hand-eye coordination and cognitive effort for Dennis.

Dennis can now walk with a walking stick. His memory has improved, and he is able to speak and write albeit with some effort. He also helps to wash dishes and cook simple dishes. Given that the prognosis for patients whose heart had stopped by the time they receive medical attention is usually poor, his recovery is truly a miracle.

My advice to other caregivers is not to give up hope. A caregiver can make a lot of difference to the patient. Adopt a positive attitude and just do the best you can.

“

Soon Fong is a truly supportive partner. She proactively sought out community activities beyond the hospital setting to engage her husband physically, mentally and socially.”

Anne George

Senior Principal Physiotherapist
Changi General Hospital



“Every day, I am thankful that Izhar is well. I know he may leave us at any time and I want to do my best for him for as long as he is with us.”

Mdm Juliah Bte Kasiman, 39

Homemaker

My son, Izhar, is an active kid who has a mind of his own and is not afraid to show it. He is, however, no ordinary 11-year-old. He cannot see, speak, sit or stand on his own. Yet, his unique personality shines through.

Izhar was born with a rare congenital disorder that caused defects to his heart, lungs, spleen, intestines and kidneys. When he was only a few months old, he underwent several surgeries to correct his heart defects. However, he suffered brain damage due to complications from the surgeries.

As a result, he lost his sight and developed cerebral palsy which impaired his muscle control, balance and movement. Izhar requires maximum assistance for all activities of daily living. To care for him, I had to learn home care procedures such as non-invasive ventilation, oxygen therapy, suctioning and nasogastric tube feeding from the healthcare team.

Despite his disabilities, Izhar has his own way of communicating with us through his moods and sounds. The years of physio- and occupational therapy have also helped Izhar gain upper body strength and significantly improved his mobility. He has figured out a way to get around our home by sliding on his back using his legs. He somehow manages to navigate around obstacles, like furniture, using his keen sense of hearing and can get around really quickly!

I have two other boys, a 10-year-old and a seven-month-old baby. I am very blessed to have a loving family and strong support. My husband, Azhar, is very hands-on with our kids while my mother-in-law is a great caregiver.

As the mother of a special needs child, I know how exhausting and challenging it can be for other parents who are in a similar situation, especially those without family support.

This is why I have been volunteering at the Cerebral Palsy Alliance of Singapore (CPAS) for the past four years. As the Chairperson for Parents Connection at CPAS, I help organise events, such as bowling outings and weekly craft activities, so that members can get together for peer support, share experiences and caregiving tips.

Beyond CPAS, I also volunteer with Project Give where we plan parties for children like Izhar. It's a safe space where parents can connect with other parents. Meeting all these families allows me to learn from their different perspectives and I'm inspired by them to stay strong.

My late mother taught me that staying strong and positive can help us get through hard times. Throughout her battle with breast and bone cancer, she always stayed cheerful and refused to let her suffering show.

Every day, I am thankful that Izhar is well. I know he may leave us at any time and I want to do my best for him for as long as he is with us.

“

Juliah never despaired or gave up hope when the doctors gave her bad news about Izhar's health. Her strength and resilience are very inspiring.”

Maryani Binte Abdul Wahab

Nurse Clinician
Children's Complex and Home Care Services
KK Women's and Children's Hospital



“He may never be able to do what other children can, but Kayden is truly a fighter... How can I give up when he is so strong in the face of adversity?”

Ms Toh Shiling, 29

Full-time Caregiver

When I was pregnant with Kayden, everything went well, and he looked perfectly healthy at birth.

The first problems surfaced when we went for a regular check-up at the polyclinic for his jaundice levels. When we told the doctor that we noticed Kayden gasping unusually when drinking milk, he referred us to KK Women’s and Children’s Hospital for further consultation.

Things escalated quickly from there. He developed a sudden fever and was warded in the Neonatal Intensive Care Unit when he was only five or six days old. One thing led to another and he even stopped breathing at one point. It was an absolute nightmare for new parents like us. I could barely make sense of everything that was happening.

Little did we know that it was only the beginning of Kayden’s battle with illness.

For the first year and a half of his life, Kayden was in the hospital almost every month. Every little infection or ailment would turn into something serious, at times even resulting in his heart stopping.

The doctors eventually discovered that he had a very rare KIF1A gene mutation, which causes serious developmental delays, compromised immunity and severe epilepsy. As a result, he requires long-term, complex care.

It was terribly depressing when we learnt of the diagnosis. Thankfully, Kayden has a wonderful medical team who has been helping us navigate this difficult journey. The nurses have been so patient in caring for him and teaching me the different procedures to properly care for Kayden at home.

Despite the grim long-term prospects, I’ve never once thought of giving up. He may never be able to do what other children can, but Kayden is truly a fighter. Even though he’s so young, he endures the multiple medical procedures patiently and bravely. How can I give up when he is so strong in the face of adversity?

Kayden is turning three next year, and his condition has improved tremendously. He now attends lessons three times a week at Rainbow Centre, where he enjoys sensory play, music and movement, and practises gross motor skills like sitting up and strengthening his neck muscles.

My husband works hard at two jobs to support our family while I care for Kayden. I gave up my job but have no regrets.

I have simple hopes for Kayden — to be able to walk, sit up, and hopefully, call me “Mummy” one day.

“

Shiling is a dedicated and loving mum, caring for Kayden round-the-clock with no complaints. Even though she knows there is no cure for Kayden’s condition, she maintains a positive attitude, collaborating with the healthcare team to adapt to the changes in his condition, acquiring new knowledge and doing all she can to improve his quality of life.”

Dr Cristelle Chow

Director
Children’s Complex and Home Care Services and
Consultant
Department of Paediatrics
KK Women’s and Children’s Hospital



“At the back of my mind, I am preparing him for a life without me — so his independence is very important. To that end, I am very proud of how he has blossomed. He has friends, lives a full and active life, and most importantly, is happy.”

Mdm Nagajothi Marimuthu, 50

Full-time Caregiver

In my mind, Kiran is still a normal child. He was born perfectly healthy in 1995 and was developing normally, until he started experiencing fits when he was three years old. Life has never been the same since.

At his worst, Kiran would have up to 30 episodes of fits in a day. Each bout of fits would cause some damage to his brain. Kiran stopped having fits when we finally found a medication that worked for him in 2005. However, the frequent fits had taken a toll, and his development had been permanently affected. The doctors told us that he would be in a vegetative state for life.

Kiran is now 25 years old. It has been a long journey for us to get to this point today, where he is somewhat independent and able to handle basic needs such as feeding and bathing himself. I will never forget how overwhelmed I was at the start, thinking about the daunting task of caring for Kiran all by myself.

I didn't allow myself to dwell on the negative, and pulled myself out of that slump because if I didn't fight for Kiran, who would? I told myself to do all that I could to help Kiran become as independent as he could possibly be.

I enrolled him in the Movement for the Intellectually Disabled of Singapore (MINDS) so that he could learn how to be a contributing member of society. For 13 years, I was also a parent volunteer at MINDS as I wanted to have a deeper understanding of his curriculum and to help other children or families who face a similar situation. Kiran now works at the MINDS Employment Development Centre assembling earphones for Singapore Airlines.

Over the years, the little acts of kindness that have been shown to us have been instrumental in helping us along this journey. One example stands out in my

mind. I always had a fear of bringing Kiran to the dentist as I have had horror stories of special needs children being tied to the dental chair to keep them down during the procedures, so I did not take him to the dentist for over 20 years! Thankfully, this fear proved unfounded as we are very fortunate to meet a wonderful care team at the National Dental Centre Singapore, who always goes out of their way to make each of our dental visits a very pleasant experience. As a caregiver, I feel it is important to cooperate with the healthcare team to do what's best for Kiran. I am happy to see the improvement in Kiran's oral health.

Through it all, I have never pitied my son for what he cannot do, as I always see him as a person who can do so much if taught properly. In fact, I was so proud when Kiran participated in the Southeast Asia Special Olympic National Games in 2017 and even won gold medal in the double bocce games!

At the back of my mind, I am preparing him for a life without me, so his independence is very important. To that end, I am very proud of how he has blossomed. He has friends, lives a full and active life, and most importantly, is happy.

“

Mdm Jothi's indomitable spirit and belief in her son is truly inspiring. She never once gave up on Kiran and was determined to help him live a full and active life. The fact that Mdm Jothi is able to love and laugh every single day is a reminder to us all to live life with a similar dose of optimism, passion and joy.”

Dr Kong Rui Ling

Prosthodontic Resident
Restorative Department
National Dental Centre Singapore



“I choose to spend my time and energy helping and encouraging others who are in a similar position, because I believe that spreading positivity comes one full circle.”

Mr Nicholas Sim, 65
Freelance Consultant and Trainer

My wife was a gentle soul who always had a kind word and lovely smile for everyone. She was a loving wife, devoted mother to our two sons, and was a successful career executive prior to early retirement. We lived a fulfilling life.

In November 2012, she was diagnosed with Young Onset Dementia at only 55 years old. The news was a tremendous shock for us. I resolved to stay strong for her and be her pillar of strength amidst the uncertainty.

I once woke up to find her crying in the middle of the night, worrying about the future. She was especially worried that she would one day forget me. I fought back my tears and reassured her that as long as I remembered her, it'd be enough.

The hardest part of this caregiving journey for me was seeing her lost and afraid while being very aware of her own condition. As her condition worsened, she had trouble telling right from wrong, and was unable to recognise alphabets and numbers. Gradually, she lost her mobility and had to rely on a wheelchair to move around. Each time she became incrementally unable to do something, my heart would break a little more.

To better care for my wife full-time, I closed down my business. It was a decision I made without hesitation as I wanted to be there for her every need – no one knows her better than I do. Today, she is totally mentally incapacitated and has lost all basic living functions.

I must admit that the loneliness has been difficult for me. My life partner whom I used to share everything with; she's here, yet not really here anymore. She is now totally dependent on me and our helper for all her basic needs.

It's easy to slip into a spiral of depression and worry. However, wallowing in self-pity has never been an option for me. I choose to spend my time and energy helping and encouraging others who are in a similar position, because I believe that spreading positivity comes one full circle. I volunteer at the National Neuroscience Institute's CARE (Cognitive Assessment and Rehabilitation) Programme Support Group to share my experience with other caregivers. I've also given a talk on the "Pursuit of Happiness" to encourage fellow caregivers and early stage dementia patients to stay strong in their journey.

There are little joys and positive moments each day so I focus on those. I take my wife out to listen to live bands play, or just go downstairs to the garden for walks. I focus on what we can still do together, rather than brood over what we can no longer do.

“

Nicholas's dedication and love towards his wife is very touching and clear for all to see. His positive attitude and generosity in reaching out to other caregivers who struggle with caring for a loved one with Young Onset Dementia is extraordinary. He has never once rejected our requests to speak with other caregivers.”

Linda Lim

Advanced Practice Nurse
Neurology
National Neuroscience Institute



“I’m getting on in age and have medical conditions... But I will try my best to stay well so that I can carry on looking after my wife for as long as I can.”

Mr Ng Buan Hian, 72

Retiree

My wife Bee Wan suffered a stroke while we were on holiday in Malaysia in 2013. We rushed her to the Singapore General Hospital (SGH) where she underwent various procedures, including a tracheostomy to insert a breathing tube to help her breathe.

Her sudden stroke came as a shock to our family and we struggled to cope with managing her care and the mounting medical expenses. Due to the stroke, Bee Wan could not speak and became bed-bound from paralysis on the right side of her body. I decided to quit my job as a hawker to take care of her. Finances were tight as we relied on the income of our only daughter Hwee Mien, who works as a shipping coordinator, to get by. Thankfully, we received financial assistance for her medical expenses.

After three months at SGH, Bee Wan was transferred to Ren Ci Community Hospital to receive rehabilitative care. For seven years, she stayed at the chronic sick unit as she also had other medical conditions including Parkinson’s Disease, kidney stones and hypertension.

Rain or shine, I would travel by public transport from our home in Bukit Batok to the hospital in Novena to visit Bee Wan every day. I sometimes cook her favourite dishes and sit with her to make sure she finishes them. I would also try to keep her mind active by talking and reading to her. As she could no longer speak after the stroke, I learnt to read her moods and gauge how she felt by observing her body language.

In 2018, Bee Wan finally got well enough to have her breathing tube removed and was transferred to Ren Ci @ Bukit Batok Nursing Home. I was initially unsure and concerned that Bee Wan would not be able to receive the necessary care at a nursing home. However, the medical team patiently explained their care plans for her and helped allay my concerns.

I am thankful that Bee Wan’s condition is much better now. I continue to visit her at the nursing home daily to spend time with her. To improve her motor skills and mobility, I encourage her to feed herself and comb her hair. We also do some simple exercises together.

As Bee Wan has been a long-time resident of the home, I have become familiar with many staff and patients there. I try to help out in the ward whenever I can and share my caregiving experiences with other patients and their families.

I’m getting on in age and have medical conditions such as high blood pressure, high cholesterol and pain in my knees. Taking care of Bee Wan full-time is not easy, and there are some days where I feel tired and depressed. But I will try my best to stay well so that I can carry on looking after my wife for as long as I can.

“

The loving care that Buan Hian shows towards his wife during his daily visits is very endearing. Our staff are also very motivated by the appreciation that he and his daughter show towards us.”

Elsie Teo

Assistant Director of Nursing
Ren Ci Hospital



“My wife, Margaret, once said to me, ‘You’d better not die before me.’ I hope to keep her company and make her laugh for as long as I live.”

Mr Riechard Ang, 81

Retiree

My wife Margaret and I have been married for more than 50 years. I believe it was fate that brought us together.

I first met Margaret in primary school when her mother, who was my Chinese tutor, brought her along to my house. My first impression of her was that she looked like a pretty doll.

Years later, we met again when she visited my school for an exhibition, but we didn’t keep in contact. The third time we met, we were already young adults. We bumped into each other at a shopping centre, and I plucked up the courage to invite her out for coffee. That’s how we started seeing each other and the rest is history. Today, we have three sons and seven grandchildren.

Margaret had always been healthy but things started to change in 2016 when she was 76 years old. One day, we were chatting and laughing over a joke while having dinner. All of a sudden, she flared up and started shouting at me.

The extreme mood swings and sudden outbursts persisted for a few days. Once, she even chased me out of the house. It got so bad that I would seek refuge at the public library, and I eventually took up a job as a security guard on the night shift just so I could minimise contact with her and avoid arguments.

I was under a lot of stress and thought of filing for a divorce. It was only when our son took Margaret to the Institute of Mental Health for a check-up did we realise she was suffering from dementia. I immediately quit my job to take care of her. I showered her, fed her, cleaned the house and kept her company. I am no superman and I admit, it was mentally and physically tiring.

As time went by, her condition deteriorated and she needed more assistance in her daily life. By then, I was also in my late 70s. In November 2017, we decided to admit her into Ren Ci Hospital @ Bukit Batok so that she could be better taken care of.

I visit Margaret everyday and spend the entire day with her. It takes me an hour to get to Ren Ci, but I don’t mind. She doesn’t eat well if I am not there with her. Margaret was a former preschool teacher, and loves nursery songs and rhymes. I often play her favourite tunes, such as Edelweiss, on my portable music player and sing with her.

Recently, Margaret stopped speaking. My wife is the smartest person I know and it breaks my heart to see her like this, but I know I have to stay strong for her. Margaret once said to me, “You’d better not die before me.” I hope to keep her company and make her laugh for as long as I live.

“

Mr Ang’s commitment and devotion to his wife is remarkable. He is constantly reading up on ways to engage persons with dementia, and readily shares his experience with other caregivers. His wife’s quiet joy is testament to his gentle care and constant presence.”

Elsie Teo

Assistant Director of Nursing
Ren Ci Hospital



“It was not easy being a caregiver but staying cheerful and positive helped. I’m glad to have been by my sister’s side when she needed me.”

Ms Amanda Pang, 46

Property Agent

2019 was a sad year for my family. We lost two family members to cancer.

My 83-year-old father died of lymphoma in October 2019. It was a shock to my family but I’m greatly relieved he did not suffer much. He passed away in his sleep about six months after his cancer diagnosis.

But for my 54-year-old sister, Poh Choo, who passed away in September 2019, it was a long and difficult struggle.

Poh Choo and I were not close when we were young because of our eight-year age gap, but we became close after she fell ill and I became her caregiver.

Poh Choo was first diagnosed with colorectal cancer in 2012, and underwent many rounds of chemotherapy and radiation therapy. She had surgery and lived with a stoma bag for about a year. She returned to work after her stoma bag was removed, and we thought she had recovered fully. Unfortunately, she had a relapse in 2015. Her cancer continued to grow and spread.

In 2018, her doctors suggested admitting her to a hospice but Poh Choo refused, so I tried my best to care for her at home.

Poh Choo lived with me, together with our elderly parents, my husband, Lucas, and our seven-year-old daughter. I learnt to administer her medications through intravenous transfusion and hired a domestic helper to assist in caring for her daily needs.

Despite being in great pain, she was very stoic and did not complain much. Once, I remember her confiding in me about her severe pain when sitting or lying down only after she had three sleepless nights. Other than the pain relief medication prescribed by her doctors, we tried to alleviate her pain through alternatives, such as Traditional Chinese Medicine and heat packs.

It was really worrying when Poh Choo had episodes of vomiting and fever, and I would sometimes panic or feel helpless. The Singapore Cancer Society (SCS) was my lifeline. SCS nurses gave me invaluable advice and followed up with us meticulously so I never felt alone.

My husband was my rock. He would make time during his work or lunch break to drive Poh Choo to her medical appointments. Even my daughter would help to keep an eye on her aunt.

Poh Choo enjoyed good food so we would go around Singapore to get her favourite food, like the Sembawang White Bee Hoon. Even though she could only eat a little, tasting her favourite dishes always made her smile. We were happy to do what little we could to brighten up her days.

After battling with cancer for about seven years, Poh Choo passed away peacefully at home.

It was not easy being a caregiver but staying cheerful and positive helped. I’m glad to have been by my sister’s side when she needed me.

“

Amanda not only had to manage her sister’s challenging medication regime, such as the daily drug infusion; she also tried to think of innovative ways to help Poh Choo whenever she developed new symptoms.”

Dr Teoh Ren Shang

Senior Resident Physician
Singapore Cancer Society



“I am glad my ‘Da Yi Ma’ has been relieved of her physical pain, and I know I have done my best. She has taught me to treasure my loved ones, and to never give up in life.”

Ms Elaine Chiang, 26

Postgraduate Student

I am blessed to have not one mother, but two.

My second “mother” is my mother’s eldest sister. I call her 大姨妈 (“Da Yi Ma”), or eldest aunt in Mandarin. She lived with us and took care of my younger brother and I since we were young, while my parents worked.

Da Yi Ma was not well-educated, and never got married. She dedicated all her time to the family; cooking, cleaning and looking after us. At night, while everyone was asleep, Da Yi Ma would clean the house. She was always the first to wake up and the last to go to bed. Even during her last days, when her entire body was swollen, she insisted on cleaning the house.

In 2014, Da Yi Ma went for a medical check-up and came home with bad news – she had Stage 3 ovarian cancer. She underwent intensive treatment and surgery to remove her womb, but the cancer relapsed in 2017, and again in early 2019, when the doctors gave her the bleak prognosis of six months to live.

I became Da Yi Ma’s caregiver in the final months of her life as I had the flexibility of time as a student. I had to learn how to manage my time – looking after Da Yi Ma in the day, and studying at night. From insurance and medical statements to palliative care arrangements, I handled all the paperwork and communications on her behalf.

When she was hospitalised, I made sure she was never alone. At night, I stayed in the hospital with her and slept on the chair. Perhaps it was her selfless and giving attitude that subconsciously shaped me, but looking after her seemed like the most natural thing in the world to do, especially after all that she had done for me.

To be honest, Da Yi Ma was really strict with me when I was younger. For that reason, we weren’t particularly close, and we drifted further when I entered university

and lived on campus. Ironically, her illness brought us closer.

When Da Yi Ma was discharged home, we spent many hours watching her favourite period dramas together. At night, I slept on a mattress in her bedroom and we would chat late into the night.

In November 2019, Da Yi Ma succumbed to her illness and passed away peacefully at home.

All these years, I had never seen Da Yi Ma shed a single tear or throw any tantrums, even when she was sick. Her strength inspired me to stay strong throughout the time I looked after her.

I finally cried on the day her ashes were scattered at sea. I miss returning home to her at the door, and the image of her watching television in her favourite armchair remains vivid in my mind. But I am glad she has been relieved of her physical pain, and I know I have done my best. Da Yi Ma has taught me to treasure my loved ones, and to never give up on life.

“

Despite her young age, Elaine was always very comfortable being the main caregiver for her aunt. She was receptive to the advice given by the doctors, and helped to bring her aunt home for her last days.”

Dr Toy Wei Quan

Resident Physician
Department of Supportive and Palliative Care
National Cancer Centre Singapore



“Life is very fragile. When bad things happen, try to change your mindset, adjust to the new normal and appreciate the little joys in life. That’s how I motivate myself to keep going.”

Mrs Wong Lee Yong, 73

Full-time Caregiver

I met my husband, Siew Chong, when I was studying in England in the late 1960s. Our courtship literally took place on the court – the badminton court. After we got married, we continued playing badminton thrice a week for many years, until he had a stroke in 2009 at the age of 67. I really miss those moments.

A few years prior to his stroke, he discovered that he had Atrial Fibrillation, an irregular heartbeat that can lead to heart-related complications such as blood clots, stroke and heart failure. However, after going through several rounds of tests, my husband was given a clean bill of health, so we thought nothing more of it.

Siew Chong’s stroke took us by complete surprise as he had always been fit, healthy and stayed active. Aside from badminton, he also enjoyed the outdoors and gardening.

The stroke left him with severe aphasia. He lost his ability to speak, write and read, even though his cognitive functions remained intact. He also became paralysed on the right side of the body.

As his main caregiver, I accompanied him to all his medical and therapy appointments. I also cooked his meals and assisted him in all aspects of his daily life. Thankfully, after five months of intensive rehabilitation, he was able to move around in a wheelchair, and could use his fingers to pinch morsels of food.

But life was tough, especially in the first few years. I suffered severe lower back and leg pain from pushing him around in a wheelchair every day. Siew Chong would also get frustrated easily and yell at me, sometimes even in public.

Ten years into my caregiving journey, I have learnt to be more patient and understanding. My husband and I also communicate a lot better now. Sometimes, I use visual aids such as photos to help him convey what he

wants. He is also able to go around our neighbourhood on his own in a motorised wheelchair.

I am always thinking of new ways to engage my husband mentally and physically. We love travelling and continued doing so even after his stroke, visiting countries such as Israel and China.

We have also been regular participants of Chit Chat Café since its inception in 2018. It is an organisation that provides a safe environment for people with aphasia to meet monthly and practise talking. We are also part of the Aphasia SG Choir, the first aphasia choir in Singapore and Southeast Asia. My husband enjoys the meetings and weekly rehearsals, where he gets to interact with others like him.

Life is very fragile. When bad things happen, try to change your mindset, adjust to the new normal and appreciate the little joys in life. That’s how I motivate myself to keep going.

“

Mrs Wong is the epitome of love towards her spouse. Once, she had a bleeding wound on her thumb but she still brought Mr Wong to his aphasia choir practice and sat through it as she didn’t want him to miss the activity that he enjoys. She also readily assists us with our advocacy work for aphasia.”

Lee Jia Ling

Speech Therapist
Singapore General Hospital



“At our age, we should take each day as it comes, look forward to the little enjoyments in life, and be thankful for all we have.”

Mdm S. Supama, 74

Full-time Caregiver

My sister, Sathamba, is two years younger than me. Despite this, she took care of me when we were younger, especially when I worked as an assistant teacher in my 20s. She cleaned the house, made sure I had freshly ironed clothes to wear, and cooked the most delicious meals. What's amazing was that she did all these while tending to her provision shop, and she enjoyed it all very much.

When she was in her 50s, she developed diabetes and was later diagnosed with liver cirrhosis in her 60s. Six years ago, she started to experience some difficulties while doing simple, everyday tasks like putting on her clothes or walking to the market. It made her very upset and she cried a lot. Her health started to deteriorate from then.

One night in 2018, Sathamba fell and hit her head while trying to get to the bathroom. She was hospitalised for a week and has never been the same since. Her falls became more frequent and her mobility worsened.

After numerous hospital visits and tests, she was finally diagnosed with vascular Parkinsonism, which led to dementia. It was a relief for us to finally know what was causing her frequent falls because we had a better idea of what to expect.

I took over the preparation of meals for the family as Sathamba could no longer go to the market independently. I know she enjoys having Indian breakfasts, so I try to make dishes like chapati for her at least three to four times a week.

Between me and our helper, we make sure that one of us is always around to tend to Sathamba's needs as she is dependent on us for all her daily activities. I usually stay up till 3am to accompany Sathamba, and our helper takes over thereafter.

Sathamba still enjoys going out on short outings, so our days are filled with visits to the nearby supermarket, mall and neighbourhood centre. We also watch cooking shows and Tamil dramas together at home.

Come to think of it, Sathamba and I have been taking care of each other for a long time now. While the reversal of roles initially felt bittersweet, we have both accepted this for what it is.

We sometimes talk about this as part of life and ageing, and that there is still plenty to be grateful for in our lives. I am thankful to be in generally good health myself, so that I can be there for my sister. At our age, we should take each day as it comes, look forward to the little enjoyments in life, and be thankful for all we have.

“

Supama is a dedicated and loving caregiver to her younger sister, Sathamba. Despite Sathamba's medical issues that require help in everyday living, Supama does it all with a smile. She has put her own life on hold to be with her sister all the time, and that she does this so joyfully is inspirational.”

Dr Meykkumar s/o Meyappan

Family Physician
SingHealth Polyclinics – Pasir Ris

Mdm S. Supama's sister, Mdm S. Sathamba, is a winner of the Inspirational Patient & Caregiver Awards 2020 — Patient Category. Her story is on page 51.



“Dry your tears, move on and be strong because there is a lot you can do for your child, who deserves to live a normal life like everyone else.”

Mdm Farah Juwita Bte Alias, 41

Homemaker

My husband and I started getting worried when our youngest son, Ilhan, could not maintain eye contact with us and refused to speak when he was about three years old. When we also noticed that he had a very high pain threshold, we knew something was not right and brought him to a doctor.

My mind went blank when the doctor at KK Women’s and Children’s Hospital (KKH) told us that Ilhan has Autism Spectrum Disorder (ASD). I have five other children, now aged between 14 to 21 years old, but nothing prepared me for this. I felt guilty and asked myself questions like, “Did I do anything wrong during my pregnancy? Did I not take care of him properly? What should I do next?”

Seeing how lost I was and unsure of how to take care of Ilhan, our doctor recommended that I enroll Ilhan in the Early Intervention Programme for Infants and Children (EIPIC).

Securing a place for Ilhan at EIPIC at SPD@Bedok was a turning point for us. The staff at SPD@Bedok patiently answered all my queries and assured me that Ilhan would receive quality and professional care there. That was the first time I felt confident and hopeful about the situation since his ASD diagnosis.

As Ilhan grew older, I wanted to enhance my knowledge on ASD to better care for him and develop his abilities. My older children suggested that I attend courses for parents of children with autism. After attending the courses, I would share what I had learnt with my family. I am very proud to say that that our close-knit family of eight bonded even stronger together throughout this journey of caring for Ilhan. We are even planning to go abroad on our very first family trip soon.

My husband and children are my strongest pillars of support. I am heartened that my older children love Ilhan and make the effort to spend time with him. They come up with a daily schedule and take turns to accompany him to the playground and soccer field to play every day.

For me, the most challenging part of parenting a child with ASD was learning to deal with contingencies. Being an organised and meticulous person, it took me a long time to get accustomed to “going with the flow” and not having things within my control. I am now much more spontaneous and optimistic.

Ilhan is now six, and he has made good progress with managing his emotions and grasping new concepts in school. With some free time on my hands now, I started volunteering at SPD@Bedok, helping with events and manning their mini library. I also talk to other parents of children with ASD to share my experience. I always remind them that it is alright to cry, but they must move on from their tears and be strong because there is a lot they can do for their child, who deserves to live a normal life like everyone else.

“

Despite her busy schedule taking care of Ilhan and five other children, Mdm Farah selflessly provides emotional support to other caregivers, lending them a listening ear and pointing them to helpful resources. We see her positive attitude rubbing off on anxious parents and calming them down.”

Kunal Kanti Ghosh

Senior Centre Manager
SPD@Bedok



“I hope that our society will continue to be more inclusive towards children with special needs. Given the right opportunities, they too, can shine in their own ways.”

Mdm Seah Shiang Ping, 50

HR Consultant

In 2017, when my daughter Kayleen was in Nursery 2, her teacher noticed she had difficulty tracing with pencil and paper and was falling behind her classmates in lessons. I got worried and brought her to KK Women’s and Children’s Hospital for a check-up.

Kayleen was diagnosed with Global Developmental Delay, which meant she would take a longer time to reach developmental milestones such as language and motor skills.

As a first-time mother, I was lost and uncertain about managing her condition. At her doctor’s recommendation, I enrolled her at Building Bridges at SPD@Bedok, an Early Intervention Programme for Infants and Children (EIPIC). I also took a six-month break from my job to focus on caring for her.

I observed that Kayleen learns and processes information differently in tasks like counting, drawing intersecting lines or completing jigsaw puzzles. Although she finds writing challenging, she has no problem with verbal memory. At the age of five, she could recite the entire Di Zi Gui, a book on Chinese classic texts.

Kayleen’s confidence and social skills have improved after attending EIPIC. She used to be intimidated by crowds and group activities. When she spontaneously danced on stage during an event, I felt so proud of her!

When Kayleen turned six last year, my husband and I had a hard time deciding whether to place her in a mainstream primary school. At her therapist’s recommendation, we deferred enrolling her for a year. In the meantime, she is attending occupational, speech and art therapy and doing well. I’m positive she will progress in her own time and way.

In 2018, I initiated the idea of setting up a resource library at SPD@Bedok. We gathered books, toys and educational materials that parents, especially those with limited means, can use to engage and guide children. I even wrote to LEGO to request for donations of building blocks and was elated to receive their positive response. I hope this will open up doors for more meaningful sponsorships to benefit our children.

I’m also involved in national-level caregiver events and focus groups for people with disabilities. As part of the SG Enable P2P Mentor Programme in 2018, we trained other caregivers to become mentors and created awareness of available support for caregivers.

Over the years, I’ve seen an increase in efforts to raise awareness of the special needs community in Singapore. I hope that our society will continue to be more inclusive towards children with special needs. Given the right opportunities, they too, can shine in their own ways.

“

Mdm Seah’s dedication to Kayleen is evident in her unwavering commitment to explore ways to help her child develop and progress. Despite the struggles and uncertainties, she continues to actively volunteer as a Parent Champion at SPD@Bedok to support other parents.”

Kunal Kanti Ghosh

Senior Centre Manager
SPD@Bedok



“I could have hired a helper to care for my mother and go to work, but I prefer to stay by her side and look after her myself. My late father would have wanted me to do this as well.”

Mr Tan Shew Sia, 58

Full-time Caregiver

My father died in 2010 after a bad fall. My mother was in her 70s then. Not wanting her to live alone, my wife and I asked her to move in with us. As my mother wanted to continue living in her own home, I eventually moved in with her, while my wife cared for our three daughters at home.

In 2017, my mother was diagnosed with tuberculosis. To care for her full-time, I left my job as a coffeeshop assistant. The first few months after the diagnosis were the hardest as she was often in and out of the hospital.

Due to her poor health, my mother did not eat well and lost weight. She was only 28 kilograms when she was admitted to St Luke's Hospital in 2018. Her dietitian helped her to gain weight and strength.

After my mother was discharged, I was determined to take good care of her. Every day, I showered her and changed her diapers. At night, I checked on her to make sure she was okay.

I also cooked for my mother and followed her dietitian's instructions closely. My cooking skills, passed down from my mother since I was a child, was put to good use. I made sure she had nutritious meals with fish and pork though finances were tight as I wasn't working anymore.

My mother attended day rehabilitation at St Luke's Hospital for a year after her discharge. Her wheelchair was too big to get on the bus, so I would wheel her to the hospital, six bus-stops away from home. When she got better and no longer needed a big wheelchair for better support, we switched to a smaller wheelchair and I was able to take the bus with her.

My mother turns 86 this year and now weighs 45 kilograms. She is in better health and is able to move around with a walking stick.

As my mother's full-time caregiver, I see my wife and children only a few times a week. I talk to them regularly on the phone and make those moments count.

The caregiving journey has not been easy and finances are tight. My former boss at the coffeeshop has asked me to return to work but my priority is to take care of my mother. I could have hired a helper to care for my mother and go to work, but I prefer to stay by her side and look after her myself. My late father would have wanted me to do this as well.

“

Shew Sia has little respite as his mother's caregiver: cooking, showering, changing diapers. He puts his mother above himself and has shown unconditional love towards her.”

Yap Mee Li

Senior Dietitian
St Luke's Hospital



“That was the first time I saw my mother cry since my father’s passing. I realised then how much I loved her, and that I would never want to make her cry again.”

Ms Nur Azizah Bte Abdul Malik, 29

Health Assistant

My father passed away from a heart attack when I was 12. Soon after, my mother sold our flat and we moved into her sister’s place.

Growing up, my mother was very strict with me. But when I started working after my ‘N’ levels, I felt like an adult and that I could do whatever I wanted. I was hardly at home and stayed out late with my friends. I picked up bad habits I knew my mother would disapprove of — smoking, drinking and partying.

Then in 2016, my mother had a stroke. She was 59 years old.

She woke up one morning and told me her eyes were cloudy. I didn’t think much of it at first, and was very shocked when the doctor gave the diagnosis. It was a wake-up call for me as I had to be her main caregiver. I accompanied her to all her medical appointments, and made sure she took her medication on time. I cooked, cleaned the house, and fed and showered her when she felt too weak.

I was a preschool teacher at that time and I loved my job. The principal was sympathetic when she heard about my situation, and suggested that I switch to a part-time working arrangement. However, I struggled with juggling work commitments and being a caregiver. The school eventually had to let me go.

I felt resentful, but I knew I had an obligation towards my mother. Who else could she turn to besides me, her only child?

Due to the mounting medical expenses, I had to tap into the savings that my then-fiance and I had set aside for our wedding. Tensions mounted between us and we argued frequently. He saw my mother as a liability and said many hurtful things in front of her. It got so bad that I decided to end our relationship and focus on taking care of my mother.

Over time, I fell into depression. I had no job, no friends and finances were tight. We ate only one meal a day, and it was usually instant noodles or rice with egg.

One night, I took an entire strip of painkillers and went to bed, hoping I would never wake up. But I did, and found myself in the hospital. A counsellor was at my bedside with my mother, who had tears streaming down her face.

When the counsellor asked if I was okay, I sobbed uncontrollably in embarrassment at how foolish I had been in trying to end my life. That was the first time I saw my mother cry since my father’s passing. I realised then how much I loved her, and that I would never want to make her cry again.

Recently, I managed to find a new job at Sunlove Home that is within walking distance from our rental flat and allows me to check in on my mother easily. I keep in touch with my counsellor, stay fit and healthy, and attend classes at the mosque regularly. God willing, with time, my mother will be healthier, and we will be financially more comfortable. I work hard every day towards this dream.

“

Despite Azizah’s personal struggles, she always puts on a warm smile to the residents at Sunlove Home. She readily provides a listening ear and sound advice to everyone she meets.”

Guna D

Assistant Director of Nursing
Sunlove Home



INSPIRATIONAL PATIENT SUPPORT GROUPS

KK Women's and Children's Hospital
Sugar Rush

National Cancer Centre Singapore
Brain Tumour Society Singapore

National Neuroscience Institute
CARE Programme Support Group
Singapore National Stroke Association



“Diabetes is not something to be afraid of. You can take control of your life and not let diabetes define what you can or cannot do.”

Ms Samantha Seet

Chairperson, Sugar Rush

For diabetes patients, a sugar rush – also known as a blood sugar spike – can be dangerous. However, a group of young patients at KK Women’s and Children’s Hospital (KKH) has given it a positive spin by using ‘Sugar Rush’ as the name of a support group to reach out to diabetes patients aged between 12 to 16. The support group comes under the guidance of the KKH Diabetes Support Group for adult patients.

“We hope that the playful reference of the group’s name gives off a sense of energy and youthfulness,” said Rajwinder Singh, one of the founders of the support group, who was diagnosed with Type 1 diabetes when he was five. Together with a group of friends he met at KKH, he started the group in 2011 to share experiences and provide a platform for young diabetes patients to interact and support one another.

Sugar Rush reaches out to young patients and their families through fun and experiential activities. One of its popular events is the Amazing Race, an outdoor activity injected with sports elements and educational tips on how to manage one’s blood sugar level while staying active. Such activities help to prepare patients for school camps, and more importantly, assure their families that it is possible for them to be active and enjoy outdoor activities, just like other adolescents.

Many patients have stayed on with Sugar Rush as volunteers even after they’ve grown up and ‘graduated’ from the support group. A few were even inspired to pursue a career in healthcare, including one who now works as a Diabetes Nurse Educator.

Ms Lim Pei Kwee, Nurse Clinician at KKH, who is also a Diabetes Nurse Educator, is full of praise for the group. “Over the years, parents have always appreciated the presence of Sugar Rush volunteers at our events. They

serve as peer leaders and young diabetes patients find it easier to confide in them,” she said. Seeing how other diabetes patients have grown up happily and healthily also puts anxious parents of newly-diagnosed children at ease.

Beyond KKH, the group aims to play a bigger role in raising awareness of diabetes and supporting diabetes patients. Over the past few years, six Sugar Rush members have had the chance to attend the Young Leaders in Diabetes training programme organised by the International Diabetes Federation. With valuable insights from the programme, they launched a variety of initiatives, including the setting up of SG DOC (Singapore Diabetes Online Community) – a closed Facebook group for members to advocate for diabetes care and share useful information.

Knowing how challenging it can be for some patients and parents to accept or manage the condition, Samantha Seet, the current Chairperson of the support group, encourages them to take the first step by reaching out for support.

“Diabetes is not something to be afraid of. You can take control of your life and not let diabetes define what you can or cannot do.”

“

As a Diabetes Nurse Educator, it is very heart-warming to see my young patients grow up without letting diabetes affect them. I am proud that they are compassionately helping others in their life journeys.”

Lim Pei Kwee

Nurse Clinician
KK Women’s and Children’s Hospital



“Over the years, some members have departed but their families still keep in touch to thank us for helping to add life to their days, and not just days to their lives.”

Ms Melissa Lim

President, Brain Tumour Society Singapore

“When I was diagnosed with acoustic neuroma (a rare type of non-cancerous brain tumour) in 2004, there were no brain tumour support groups in Singapore. I struggled emotionally during my recovery journey and resolved to do something to help other patients and caregivers when I got better,” said Melissa Lim, founder and President of the Brain Tumour Society (Singapore) Limited, also known as BTSS.

Founded in 2014, BTSS meets once a month where patients, caregivers and volunteers gather to lend support, and organise educational talks and activities to raise public awareness of brain tumours and the effects on patients.

“BTSS empowered me with knowledge and gave me courage to help my wife live the rest of her days well,” said Peter Koh, a member of the group. He was the caregiver to his late wife who was diagnosed with a brain tumour. “Even though she has passed on, I continue volunteering with BTSS to help other caregivers.”

Peter is a Befriender to fellow member Barry Yap, whose mother suffers from the same kind of brain tumour as Peter’s late wife.

Beyond the friendship and emotional support, Barry also got a part-time job through BTSS as a tuition supervisor to children under the BTSS Tuition Programme. This was a great help to him as he had to leave his previous job to care for his mother.

BTSS also provides financial assistance to members. One of the beneficiaries is Smyth Woo, who is paralysed on one side of his body due to his brain tumour. With the help of BTSS, he managed to get a motorised wheelchair to help him move around independently.

With more than 300 members today, some smaller sub-groups that focus on specific patients and caregivers have formed. One example is the parents support group.

“Children who suffer from brain tumours are often left with side effects which make returning to normal life challenging,” explained Jackie Lee, whose daughter is a brain tumour survivor. “We hope to work with stakeholders to help these children integrate better into schools upon their recovery.”

“There is still much that we can do and I am excited at the prospect of introducing new initiatives in the next few years. We are working with doctors to bring in new treatments for brain tumours, and we also have more members stepping up to drive key initiatives,” said Melissa.

“Over the years, some members have departed, but their families still keep in touch to thank us for helping them to add life to their days, and not just days to their lives. This is what keeps us pressing on.”

“

BTSS has held firm to its mission of connecting, befriending, enabling and empowering brain tumour patients and their caregivers, to help them live strongly so that they can give back meaningfully to others in the community.”

Dr Tham Chee Kian

Senior Consultant
Division of Medical Oncology
National Cancer Centre Singapore



“CARE Programme Support Group is a wonderful community that has been a source of comfort and strength for caregivers of dementia patients like myself.”

Mdm Loh

Member, Cognitive Assessment Rehabilitation (CARE) Programme Support Group

Over the past seven years, National Neuroscience Institute (NNI) has seen an increasing number of patients aged 65 and below with young-onset dementia (YOD). Its youngest patients are in their late 40s, many of whom are still working and have young families when the disease sets in.

These patients face substantial health, social and financial problems, as well as a diminished quality of life. Their caregivers are often young, with some lacking family and community support.

In 2013, the team at the NNI Neuroscience Clinic initiated the Cognitive Assessment Rehabilitation (CARE) Programme Support Group to help caregivers of dementia patients. With the increase in YOD patients, a good proportion of young caregivers make up the group.

NNI has over 500 patients with YOD on active follow-up. The support group holds regular sessions where members learn more about the caregiving journey from healthcare professionals and fellow caregivers. These interactions provide emotional support, allow for better stress management and reduce the sense of frustration and loneliness in caregivers. The group also organises talks to equip caregivers with knowledge and techniques, and provide them access to resources.

One of the group’s core organising team members Ms Nyu Mei Mei, Senior Staff Nurse, NNI, said, “The talks and discussions facilitated by CARE staff and sharing by caregivers are very useful and carry more weight since they offer first-hand accounts of what they go through.”

Mdm Loh, an active member, shared that the support group is a wonderful community that has been a source of comfort and strength for caregivers of dementia patients like herself.

The profile of caregivers in the group is diverse; from spouses, siblings, parents and children, to neighbours of patients. They all share one thing in common — a deep concern and enduring commitment towards the person they look after.

Ms Eveline Silva, Principal Psychologist, Department of Neurology, NNI, recounts, “We had a participant who was the sole caregiver for his wife with YOD. He was diagnosed with terminal cancer, and was concerned for his wife. Knowing that he could no longer take care of her, he ensured that her care arrangements were in place before he passed away. He brought in his wife’s siblings into the support group so that we could guide and support them in her care. That allowed him to depart in peace.”

CARE also organises outreach events and an annual caregiver appreciation outing to raise public awareness of the condition.

“

Caregivers in the CARE Programme Support Group offer one another comfort and encouragement, and have established a special bond, often meeting beyond support sessions over coffee and other social activities.”

Assoc Prof Nagaendran Kandiah

Director, NNI Dementia Programme
Senior Consultant, Department of Neurology
National Neuroscience Institute



“We have seen survivors overcome the odds to get back on their feet, and met dedicated caregivers who never gave up on their loved ones. There’s so much we can learn from their resilience and fighting spirit.”

Dr Ng Wai May

*President, Singapore National Stroke Association and
Deputy Director, Nursing, National Neuroscience Institute*

When he was 40, Mr Michael Quek suffered a stroke which affected movement on the right side of his body. Hit with the sudden loss of mobility, he was devastated and depressed. Like him, many stroke patients face similar challenges.

With grit and determination, Michael managed to pick himself up. Unable to return to his job as an electrician, he took up a multimedia course at SPD, a local charity that helps people with disabilities integrate into society, and is now working as a photo editor at an events company. He wanted to use his experience to motivate other stroke survivors. Through SPD, he got to know the Singapore National Stroke Association (SNSA), and is one of its most active volunteers today.

Established in 1996, SNSA is a national support group for stroke survivors and caregivers. It has 600 members which comprise volunteers and healthcare professionals. SNSA focuses on supporting stroke survivors and caregivers, and actively raises public awareness on stroke prevention and early stroke detection.

Under SNSA’s befriending services, volunteers like Michael reach out to stroke survivors recovering in hospitals. “I share my story to give them hope and encourage them to find support through SNSA,” he said. “Joining SNSA has helped me realise that being disabled doesn’t mean one is ‘unable’. There are many things I can do, though at a slower pace.”

Dr Ng Wai May, President of SNSA, shared that Singapore has about 8,000 new cases of stroke each year, with increasing incidences among the younger population. SNSA hopes to reduce this number through its stroke prevention and detection awareness programmes,

which play a part in early clinical intervention for the disease. It also wants to reach out to more survivors to help them adjust to life after stroke.

“Stroke survivors have a long journey of rehabilitation and reintegration into society. They face different challenges from regaining bodily functions to going back to work or learning to be independent. They and their caregivers need a lot of social and emotional support from their family and the community,” she explained.

SNSA also organises a twice-monthly “LIFE after stroke” programme that comprises talks, outings and exercises. These activities allow stroke survivors and their caregivers to enjoy light-hearted moments together, pick up practical post-stroke care tips, or simply lend a listening ear to others.

“The key is not to lose hope,” said Dr Ng. “We have seen survivors overcome the odds to get back on their feet, and met dedicated caregivers who never gave up on their loved ones. There’s so much we can learn from their resilience and fighting spirit. SNSA wants to walk the journey with them and cheer them on.”

“

SNSA has helped countless stroke survivors and their caregivers beyond what medicine alone can do. Many, in turn, support others facing similar challenges, despite their own trying situations. Their passion is admirable.”

Tye Siew Noi Janis

Senior Nurse Clinician (Advanced Practice Nurse)
Neurology
National Neuroscience Institute

