

# Caregivers' *journey*



# PREFACE

*As a caregiver, one embarks on a unique journey that can be both challenging and rewarding. It is a journey filled with ups and downs, joys and sorrows, despair and hope. Caregivers often put their own needs aside to care for a loved one.*

*This short collection of caregivers' journeys is a testament to the incredible strength, courage and resilience of those who have taken on this important role.*

*To all caregivers out there, your dedication, compassion and selflessness are truly inspiring. May this collection serve as a source of encouragement and support for those who walk the path of caregiving.*

*CPAS Social Work Department*



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## — Celia's Story —

### Caregiver to 4 years old daughter with Autism Spectrum Disorder

Fear and denial are just some words to describe how we felt when we got her diagnosis. Emma, our beautiful and bright-eyed daughter, was diagnosed with speech delay at 18 months. When she couldn't manage 'papa' and 'mama', we knew something was not right.

Who could have prepared us to be parents, let alone parents of a child with special needs. Our world collapsed, and even in all that confusion, we knew there was no time to grieve. We quickly picked up our phones to Google and watch as many YouTube videos as we could to get educated on her condition. My husband and I also eventually learnt that it was not just about equipping ourselves with the hard skills but also conditioning ourselves for the soft skills required in caring for Emma. That was the most difficult part of our journey, and I am sure many caregivers can agree on that.

Patience is not in my DNA. I struggled daily, trying to communicate with my two-year-old without getting any eye contact or a reply. Often it was just my voice echoing back at me whenever I tried to engage her. Dealing with her frequent meltdowns drained me physically and mentally. To recover and recharge, I would indulge in a big scoop of ice cream or grab a few cookies. As caregivers, we do what we must to fuel ourselves as we are running a marathon, not a race.



My husband and I also felt very alone in our journey. We yearned for some kind of support- a community that could identify with our struggles and also one to get advice and help when we needed them. The turning point of our journey was when we were introduced to EIPIIC programme, and a vacancy opened up at CPAS for Emma.

Like a well-nurtured plant, Emma started to flourish and bloom with EIPIIC. She was taking well to the intervention and her developmental progress was very encouraging. I also felt supported with a team of professional teachers, therapists and social workers that were passionate and very helpful to offer suggestions and advice whenever I needed them. My emotional tank was also full as I got the opportunity to meet some mothers who openly shared about their caregiving journey.

Over the past two years, my journey has been far from dull. Every day I learn and adapt with Emma. I have also grown to be a better version of myself and constantly evolving to tackle new challenges. This experience has been very humbling. I have to admit that as hard and challenging as daily living gets with caring for Emma, I would not want it any other way.

Emma has brought out the best in me and has proved to me on many occasions that her condition does not define, limit or withhold her. The sky is her limit, and I cannot wait to see what lies ahead of us as we journey on with faith.

**The grass is not 'greener' on the other side  
- it is just another shade of green**

- Annika Sorensen

## Deepa's Story

### Caregiver to 6 years old son with Global Development Delay and Epilepsy

My son is 6 years old this year. We are still trying to get a diagnosis for him. He comes under the umbrella of Global Development Delay and has epilepsy.

I have been a caregiver for the past 6 years. It has been a mix of ups and downs. In the initial stages, it was difficult, but it has definitely gotten much easier over time. Challenges I faced were difficulty trying to understand my child and his needs, trying to cope with the external pressure like comparing my child with others, the fear of what my son's future would turn out to be and facing people when I brought him out to places.

Over time I stopped comparing my child and understood that he needs to grow at his own pace. The acceptance of my child and the understanding of him, helped in the transition of making this journey easier. We celebrate all the small progresses and wins. For me, all that matters is whether my son is making progress from yesterday, be it a very minor thing, we will still celebrate it as it is still a step forward. I started taking each day at a time and living in the present moment instead of worrying about the future. After all each day adds up to the future!

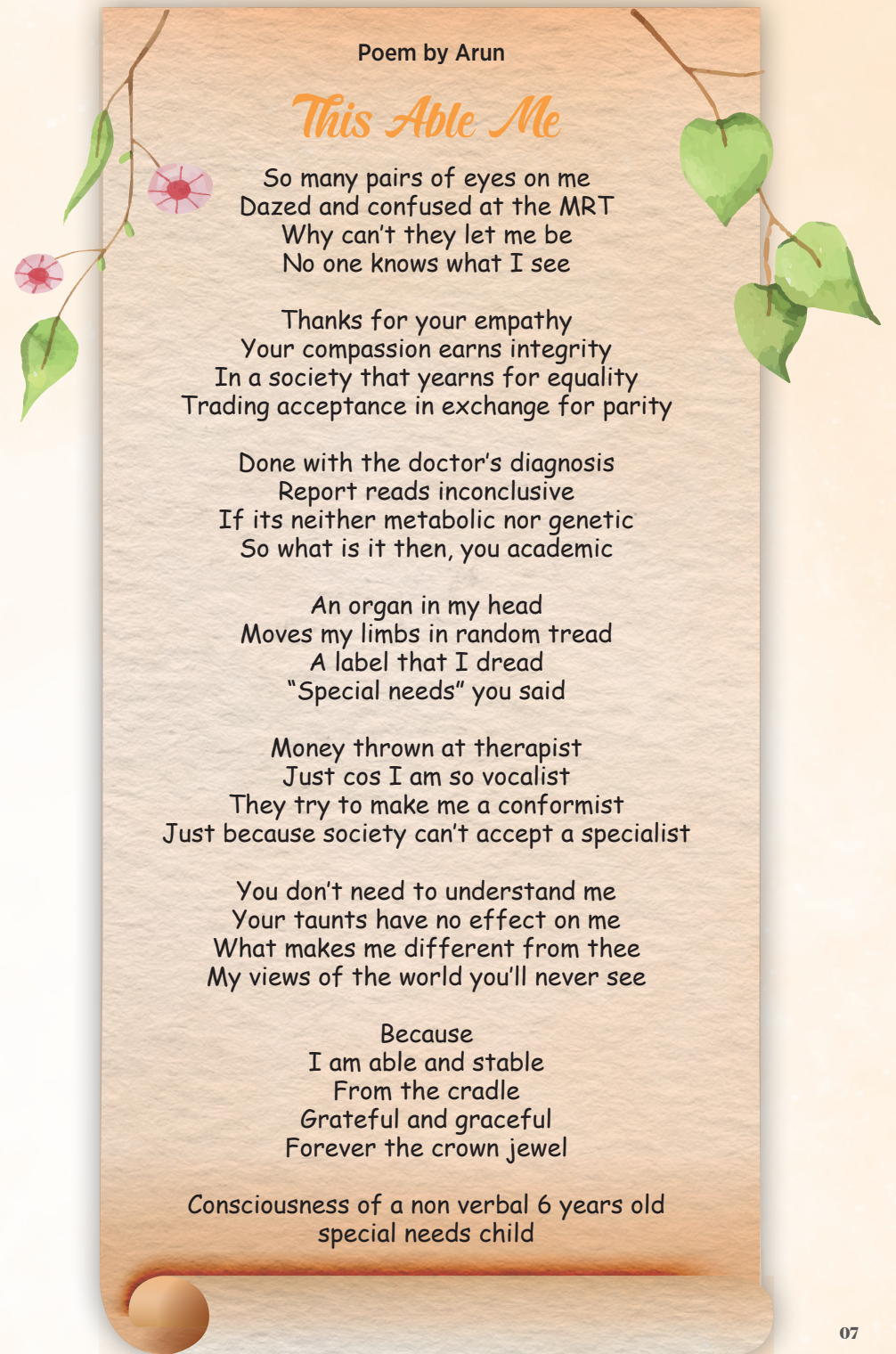




I started including my parents and sibling in discussions and updates on my child's therapy sessions / classes. My parents started helping out with my son, fetching him from therapy sessions, sitting in to watch what is being taught and now they have learnt how to handle him better. I am grateful for the support system that I have, as it allows me to get a break and even go for a holiday. I usually take the time to do something for myself when my son goes to school and recharge myself. I go for cycling, yoga and shopping at times.

Every child is different and so is the journey of every caregiver. Do not compare your child, learn to accept your child and provide him / her with every opportunity to grow. Build yourself a good support system so that you can take care of yourself. The journey is not easy but do not give up, it will get easier from where you started. Take each day at a time and start living instead of fearing of what the future might be. Find happiness in small wins, celebrate them! All that matters is the happiness of our children.

**When things feel overwhelming:  
1 day at a time, 1 task at a time,  
1 thought at a time, 1 moment at a time**



Poem by Arun

## *This Able Me*

So many pairs of eyes on me  
Dazed and confused at the MRT  
Why can't they let me be  
No one knows what I see

Thanks for your empathy  
Your compassion earns integrity  
In a society that yearns for equality  
Trading acceptance in exchange for parity

Done with the doctor's diagnosis  
Report reads inconclusive  
If its neither metabolic nor genetic  
So what is it then, you academic

An organ in my head  
Moves my limbs in random tread  
A label that I dread  
"Special needs" you said

Money thrown at therapist  
Just cos I am so vocalist  
They try to make me a conformist  
Just because society can't accept a specialist

You don't need to understand me  
Your taunts have no effect on me  
What makes me different from thee  
My views of the world you'll never see

Because  
I am able and stable  
From the cradle  
Grateful and graceful  
Forever the crown jewel

Consciousness of a non verbal 6 years old  
special needs child

## Wei Lin's Story

### Caregiver to 9 years old son with Right Spastic-Dystonic Hemiplegia, Scar Epilepsy

I have been a caregiver to my son for 8 years. When my son was just one and a half years old, he had an abnormal ruptured blood vessel, causing bleeding in his brain. The surgeons had to remove a small part of his right frontal skull and a small part of his brain to make space for his swelling brain which left a scar on his head. His life was saved but we did not know when he will be able to walk or talk again. We were not prepared on how to care for a child with disabilities. We had to quickly adapt to my son's caregiving needs which was our priority.

I was blessed with family members, especially my mom and my mother-in-law, who have supported me a lot during this difficult period with practical help. They took turns to come to my house daily to help me care for my son while I was working part time. They shared my burden so that I can concentrate on other things such as my work, son's medical and therapy needs, and still be a present mother for my elder son who was attending preschool then. Through these interactions, my mom and mother-in-law eventually became good friends with each other. I also grew to understand my mom and my mother-in-law better.



I found peace in my heart and strength to carry on through my faith in God. A dear sister-in-Christ journeyed closely with me. She prayed with me and helped me find a spiritual community who also supported my emotional and spiritual well-being.

However, I did feel burnt out from working part time and caregiving at the same time. Subsequently, I decided to resign from my work and be a full-time caregiver to my son. It was not an easy decision to switch from a dual income household to a single income household. But I felt strongly that I wanted to spend my time to help my son to learn, so that he can achieve a better quality of life when he grows up. I could do so because my husband was supportive of my decision.



Looking back, I am also thankful that my son was able to go for speech, physiotherapy and occupational therapy monthly at the hospital. We had help from the social worker, who introduced us to the early intervention programme. My son started attending EIPIC at 3 years old, and now he is attending junior programme in CPAS school. These programmes are crucial to my son's development.

From there, I learnt how to be a resourceful caregiver. I would seek help from the teachers/therapists in the areas that were challenging for me, such as motivating my son to do the therapy activities at home and how to improve my son's daily living skills. It is important to replicate the learning activities at home with my son. My son made improvements as there is familiarity and consistency in the skills that my son needs to acquire both in the school and home setting. CPAS has a team of dedicated teachers and therapists who adopt the Trans-Disciplinary approach. It helps me to enable my son to apply what he had learnt in school into the home setting. It allows more collaboration between the parents, teachers and therapist. Skills such as transferring from a kayewalker to a chair, and how to walk safely with the quadstick were also taught to my

**My caregiver mantra is to remember:  
The only control you have is over the changes  
you choose to make**

– Nancy L. Kriseman

son in school. After that, the teachers will show me videos of how it was done in school and provide me with feedback on how I can carry out these activities with my son at home safely.

By God's grace, my son was able to make many significant improvements over the last 8 years. From not being able to sit up on his own, to being able to stand on his own, and now walking a few metres with a walker. He can even run when he is using the running frame in school. Even though he is non-verbal, he communicates to us through a communication app in the iPad. His physical limitations do not stop him from doing things that he loves to do. He is a cheerful boy with an infectious smile that will make your day. He is full of joy, and he loves to interact with people.

Through these 8 years as a caregiver, I have learnt from my son, that there is so much more love and joy to experience and give in life. It is about being surrounded by the love and care from the people who loves us and God's unfailing love for us. Because of that, we have hope and strength for each new day.



## Ni Jian's Story

### Caregiver to 15 years old daughter with Neonatal Encephalopathy

My daughter is Jolene. She is 15 years old this year. I have been a full time caregiver for 15 years starting from Jolene attending the Early Intervention Programme for Infants and Children (EIPIC) to CPAS Special Education School now. Jolene's condition was the result of lack of oxygen during birth. Back then, we prepared ourselves that she could suffer from some brain damage due to lack of oxygen. She was diagnosed with Neonatal Encephalopathy.

Jolene started attending EIPIC very early. Since then, till now, we have been quite confident in taking care of her. My biggest worry now is that Jolene is growing up and getting heavier each day and that I do not have a helper. It is challenging when it comes to transferring Jolene. Hence, we are in discussion with CPAS Occupational Therapist to explore various suitable hoists to help with transferring. In School, the teachers and therapists are very helpful. Jolene has benefitted a lot from the Trans Disciplinary Approach. I learnt from the teachers and therapists and we tried to maintain Jolene's exercise. As I am a full-time caregiver, whenever Jolene has therapy sessions, I will be there, and I learnt from the therapists and applied it at home. It can be very draining physically consuming a lot of my energy.

We celebrate Jolene's birthday annually in School with her friends and family members at home. We also planned for annual overseas trip before the Covid-19 pandemic. During

these trips, we tried, within our physical strength, to let Jolene experience different things. I feel Jolene is able to comprehend a bit of her surroundings. She is happy whenever she is outside. We also join external activities, such as play buddy. Every Saturday, we will join some other children with special needs to do some simple exercises or play some simple games.

I came from China. Most of my relatives are in China. My paternal family has given me a lot of support. My father-in-law drives and fetches us from School, my mother-in-law prepares the lunch as she knows I do not have the time. During the weekend, I am able to join some activities in the CC. My In-laws offer to help to look after Jolene when my husband is not free. Basically, I am able to balance between my 'me time' and taking care of Jolene. Self-care is important.

In CPAS Social Work Department, there is a parents' room where caregivers can meet up with other caregivers to do some activities together. It is a nice space and good respite for us, caregivers. I will not seclude or isolate myself. I will join CC activities and get to know people outside the special needs community.

I have learned a lot from other caregivers in this parents' room. One aspect is siblings. I learnt that we should not focus mainly on the child with special needs. We should also be mindful of siblings' feelings. I have learnt from these experienced caregivers, and it allows me to take note of certain aspects earlier. For example, how to handle when



your child with special needs starts having menstruation. Some of these caregivers shared experiences how they managed these and it prepares me when the situation comes.

It is indeed challenging to take care of these children with special needs. Since it happened, we should accept it and try our best. Children have different needs. Some are slow in learning, some are physically challenged, like Jolene. Within our limits, we try our best to help her improve. Even though you tried, the results may not be what you expected. Do not be discouraged, just continue. The development of some of these children with special needs may slow down as they grow older. You may see a lot of improvement when they are younger, but when they grow older, you may not see much improvement. Do not give up, we should press on with the exercise so that the muscle tone can be maintained.

Do not neglect your family, especially your spouse. If you have a helper or someone to look after your child with special needs, you should try to have couple time. If you have no helper, try to find time to communicate with each other. Communication between husband and wife is very important.

Importantly, do not isolate yourself. Bring your child out and learn not to be bothered by looks from the public. Stay positive.

(Translated and Transcribed from oral account)



## Terry's Story

### Caregiver to 16 years old son with GDD, Pine Blastoma (cured) and Growth Hormone Deficiency

Ethan was diagnosed at 4 years old with brain tumour. I was on my maternity leave then. It was tough. The initial 2 years was most difficult as he went through his treatment. He had to remove his tumour and undergo chemotherapy and radiotherapy at the age of 5. The first two years was difficult. We did not have much time to think as we were struggling to save my child's life. We bit the bullet and went through it. Basically, we were at hospital most of the time. Ethan's treatment finished at 6 years old. At that time, he was non-verbal and not mobile. He could only blink his eyes. We targeted at intensive therapy sessions for him, to get him back moving again.

It was only then, the sense of hardship kicked in. Thankfully, the therapists at KKH took baby steps to help Ethan up and running. Ethan's younger brother learned walking quite quickly as he went through the therapy with Ethan. In Singapore, the support has been there. Ethan started walking 2 years later at the age of 8.

Look forward to an achievement to overcome hard times. Ethan did a lot of speech related therapy but there was no sound produced. We thought he lost his speech till one day he was very excited and shouted '5', which was his favourite number.



**It is not the load that breaks you down.  
It's the way you carry it**

- Lena Horne

These are the encouraging outcomes that will overcome all the hardships that you faced. Look forward to all these positive outcomes, it may be little but it is still an achievement.

I had to resign from my job after my maternity leave and switch roles from a career woman to a caregiver after Ethan was diagnosed. It was hard for me. Back then, I had to accept that my husband was the sole breadwinner. He had to travel a lot. So my in-laws came and helped whenever they could. My husband and I shared different roles. He takes care of all the academic matters of Ethan's brother, and I take care of Ethan. That was the family's support system.

When Ethan approached 12 years old, he was enrolled into CPAS School. I got to know other caregivers in CPAS school. The parents are warm. We participated in Parents at CPAS (P@C) and we get support from one another. We have some respite through various activities during the time when the children are safe in school. This is a part of 'me time' and I get re-charged.

Ethan has enjoyed his time at CPAS School. Besides encouraging teachers, he has a group of therapists to teach and help him. The Trans-Disciplinary Home Collaboration Programme is a good programme where students get to practice the goals in their home environment. Caregivers learned from the therapists and coached their children at home. It is a good project.



Caregiving journey is a process that we go through in various stages. The first stage is acceptance. After accepting the situation, we plan how to help the child. Do plan reasonable goals. Do not stress yourself and your child. As you see that your child is able to reach achievable small goals, then you plan for longer term goals. Initially, there were moments where we have to deal with a lot. We have to deal his meltdowns, his hormonal changes, his behaviour etc. If we looked at it strictly, there were a lot of things to address. However, pick one thing at a time. Even at the end of day, certain things may still not be resolved but we just have to take one thing at a time. If not, you would end up stressing your child and yourself.

Ethan had a meltdown every day in the past. Now, if he has meltdowns only once a month, I consider it an achievement and I celebrate. Just like his speech, he started with one word, now he can use 3-4 words although he cannot speak like a neurotypical. To me, seeing your child happy is already a motivation.

Some parents are very conscious of how people in public look at them when they are out with their children with special needs. Because of this, some caregivers stay at home. Do not be too bothered as we cannot control their looks, but we can choose our responses to it. Compared to a few years ago, there have been a lot of campaigns on inclusiveness. The public are now more aware of special needs and more receptive.

(Transcribed from oral account)

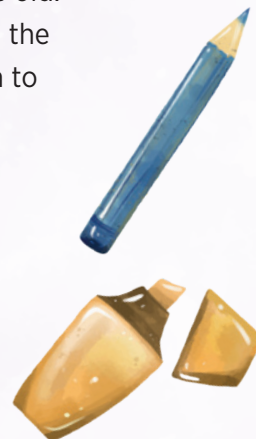
# Babelyn Tan Nieva's Story

## Caregiver to 24 years old son with Triplegic Cerebral Palsy

During my 28th week of pregnancy, 24 years ago, I had to undergo an emergency caesarean section. I gave birth to a premature baby boy who was immediately attached to several tubes and placed inside an incubator. I had to be especially strong at that time since my husband and I were told that he had only 24 hours to live, as both his lungs and heart were not fully developed then. I prayed throughout the entire ordeal, and it strengthened my faith. I took every opportunity I had while he was in the intensive care unit, to console and support my son through my words and songs.

Adrian miraculously made it out alright, and by the age of 6 months old he started to have occupational therapy (OT) 3 times a week as prescribed by his child developmental doctor. I noticed that he was squinting, so I had his eyesight checked. It was corrected through surgery when he was 10 months old. By the age of 2 years old he still had poor balance, and the doctor confirmed that he had cerebral palsy. He began to have physiotherapy sessions in addition to his OT.

When he was 4 years old, we came here to Singapore. It took time before I was able to find a child developmental clinic. I brought him to Jurong Polyclinic and KKH wherein I was



advised to enrol him into CPAS. He was accepted to study at CPAS. When he reached 7 years old, I thought of transferring him to a mainstream school so that he would be exposed to the norms in a regular setting. Luckily, he was accepted in a primary school near our place. Fortunately, when I informed the school principal of CPAS and his teacher about the news, they arranged for him to sit in a mainstream primary school nearby CPAS to prepare him for the transfer. The school administrators, teachers and therapists were of great help. The group strategized and helped Adrian in a way that would be best for him. I also prepared Adrian and myself for the challenges we might encounter in the mainstream.

Throughout his schooling years, up to tertiary education, I was with him even in the classroom. Due to his physical disabilities and visual impairment, I helped and assisted him in doing things. At home, I revised the lessons with him. In a way, my role felt like his tuition teacher. Hard work pays off! We were so happy when his PSLE results came out. He qualified for express stream for his secondary education!

## We rise by lifting others

- Robert Ingersoll

I have been his primary caregiver since his birth. Having said that, I was able to see the needs and challenges of a child and a family with such condition. We should have a lot of patience, understanding, courage and for me, faith and religion played a huge role.

Being a caregiver to someone with special needs is not easy. Especially in my situation where I still have 2 other kids and we did not have a helper then. So, I was the one who did the household chores, the cooking, the caring and the teaching of the 3 children. When they were still young, after all the chores were done for the day, I would gather them and we would read aloud story books and discuss about what we have read. Sometimes we also sing together! This relaxed us from the exhaustion after a whole day of activities. On long school breaks, we would go for a holiday, have fun and recharge. On some occasions, I would also go out with my friends.



What really keeps me going is my faith. There were times that I really felt so exhausted but when I pray it lightened my day. For those like me, taking care of someone with special needs, we should be thankful that somehow we have the opportunity to help someone in need. Keep on thinking and believing in the positive side of life. Another thing is acceptance. Accept the reality be it good or bad, and do something about it to make things better.

Being a caregiver, I learned to have more patience, understanding, courage and empathy, especially to those who have special needs. All of us are unique. All of us have our own strengths and weaknesses. Learn to find our strengths, focus and enhance it. Be caring and loving.

## — Germaine's Story —

### Caregiver to 25 years old son and daughter with Cerebral Palsy

I have been a caregiver for 25 years. I am a mother of quadruplets. 3 out of 4 of my children are diagnosed with very severe cerebral palsy. There are a lot of challenges during the caregiving journey. Financial stability, well-being and needs requirement of all my children are some of the challenges.

Each of my three children has different degrees of severity of cerebral palsy. Getting a helper is also a challenge. Finding one who puts her heart and soul in taking care of my children is also one of the challenges. But I do have a lot of support from my friends. They walked with me through the tough times. I remembered when I was separated from my ex-husband, the biological father of my children, I had to put up at my friends' place for 10 solid years, without having my own house. These friends are the ones who helped me even until now. Not forgetting the social workers' help. The medical social workers help to cover the medical fees of my children. In CPAS, Social Work Department and Adult Services have helped me and my family.

Either I am very lucky, or my children are very lucky, we have wonderful helpers who have been with us for at least 18 years. All these help means a lot, it helped me pull through the toughest time. Of course, including the joy the children bring, there is a drive to move forward.

**Like airplane passengers, let's not forget to put on our own oxygen masks first ... we are no good to our loved ones if we collapse under the strain**

- Peter B.

For me, for the past 20 odd years, the important thing is do not sit there and think about problems. Living happily is important for these children. If you keep sighing and doing unhealthy things, the children will be affected. Life will be difficult to move on. A positive mind is important. When others are down, I will use myself as an example. If you think you are in bad shape, what do you think about my plight. I want to encourage caregivers of children with special needs that caregiving is not an easy task but everyday counts, keep a positive mind. Not every day is going to be a sunny day. Think of the happy time instead of looking at the negative things. My children's names are also a reason to keep me going; HOPE - Harald, Oliver, Paul and Elaine.

I enjoy baking. It is also part of my self-care to 'switch off'. It does not matter whether the end product is nice or not. For me, it is a kind of release, and to de-stress.





I have a few good supportive friends who treated me like their sister.

They supported me in many ways. When they find that I am very stressed, they will bring me for a holiday, fully paid for. Financial support mostly comes from assistance from social workers. I have many good friends and I am not alone.

For new caregivers, the initial part is always the toughest, most difficult. Do not enclose and isolate yourself. I did that initially. But I find that if you isolate yourself nobody will know what you are going through. You have to open up and help will come from different directions. Be positive, it is not the end of the world. The more you dwell on negative things, the more negative you will be. It does not help.

(Transcribed from oral account)

## **Mrs Tan's Story**

### **Caregiver of 26 years old daughter with Hydrocephalus**

#### **Medical Background**

My 26 year old daughter, Faith, was born with hydrocephalus, a condition whereby the fluid in the brain accumulates and adds pressure to the brain tissues. She had 5 brain surgeries in the span of 7 months after birth and also contracted bacteria meningitis as well as suffered a stroke. She manifested epileptic seizures diagnosed as West Syndrome on her 9th month due to the much scarring of her brain. She is still having seizures though much less frequently now.

#### **Journey**

Faith had been diagnosed with cortical blindness, profound hearing loss on both ears, impaired cognition, global developmental delay, hemiplegia on her left limbs as well as hypertonia. She was enrolled in the EIPIC at Rainbow Centre when she was 18 months. The twice weekly sessions became very important to me as they provided an avenue for me to learn to understand her condition and the exercises and activities needed to help her. The teachers and therapists were my encouragement and support during the early years. The EIPIC school brought me to a world that was unfamiliar to me. But it was a world that provided a 'normal' and 'safe' environment for Faith and myself as a parent. It is in the school that we do not feel judged and our children are not stared at. The weekly hydrotherapy sessions provided all the sensations that Faith needed to awaken her and it stimulated her enough to move her limbs voluntarily.

### Hydrotherapy/Swimming

Faith becomes a different person in the water. She is alive and alert in the water. I believe it is the freedom the water provides her. We hinge on this motivation to help her learn skills like clasping her hands over the railings which she later applied to holding on to the railings for support when learning to walk. While swimming, she also learnt the stepping motion of the legs which helped a lot when she was taking her first steps on land.

Her head control that had been lacking was also strengthened as she had to lift up her head in the water. The spasticity in her left limbs were also reduced through the consistent hydrotherapy. The years of perseverance paid off and now Faith is able to swim unaided in the pool and is able to hold a Kaye walker frame to walk on her own. This potential in her was really unexpected and I am glad we did not give up in discovering a bright spark in her.

### Family Bonding

Our special needs child may have brought much tears of worry and anxiety, but what supercedes this, is the love, trust, care and concern for one another in the family that having a special child brings. My three older children learnt at a very young age, the fragility and preciousness of life. They learnt to treasure the health of their baby sister as well as their own. They appreciate the value of a good and healthy brain. With this sister with special needs, they all become STARS, Siblings That Are Really Special, overnight. They matured



early, learning to be responsible and self-disciplined so that their parents need not worry about them. I see this as the Power of the Powerless. It was a powerless baby that changed and brought out the best in each of us. They grew up loving their sister, concerning themselves with her needs. They are now happily married and her young nephews have been her source of amusement.

### Faith at CPAS

Faith graduated to CPAS when she was 8 years old. It was here that Faith gained more independence and developed some self-help skills. I am thankful to the teachers and therapists here who taught me to be far sighted and see a future in Faith. They persisted in teaching her to self-feed, relate socially and appropriately, increase her mobility skills and to progress in her communication skills. She's definitely more responsive and aware of her environment now. When she was 21, CPAS DAC offered her a place in the Day Activity Centre. At this centre, she continues developing and growing her daily life skills. The Centre offers a programme that surpasses our expectations for each individual client and she is a work in progress under their care. As she grows, she does develop inappropriate behaviour such as pinching anyone near her and hitting herself at times. We are still finding a permanent solution. I am so grateful to the patient and very understanding teachers, therapists, wardens and trainers who are all collaborating with one goal to help her.

**Things turn out best for those who make  
the best of the way things turn out**

- Anonymous

We enjoy Faith one day at a time and we refuse to be overly worried or anxious about her future and matters beyond our control. I am just so happy and thankful when I go to Faith every morning sees her awake and smiling.

Though the obstacles and struggles may be frustrating as she grows older, I am thankful that it has not been a lonely and hopeless journey. My faith in God as well as the people that Faith has brought us in contact with, has been an enriching, heart-warming, and eye-opening experience. I have received so much help and support from the schools and Day Activity Centre through the years, it has given me some respite to enjoy some "me time". I thank the physiotherapy department for accepting me to help out in their hydrotherapy sessions. Engaging with children in the pool has been fun and rewarding. Together with Faith, they have brought me to a world whereby I experience the uniqueness and preciousness of every child, handicapped or well and their strength, courage and resilience to face the challenges, hardships and uncertainties in life. And last but not least, Faith has been mine and my family's greatest teacher. She has taught us to love unconditionally; to give unreservedly, to value life and to be contented as we count the blessings each day brings.



A Poem by Mrs Tan

"She never calls me Mama"

It's been 26 years  
But she never calls me Mama  
She is someone who has gone through  
much head trauma.  
She survived them all despite the medical drama.

She never calls me Mama.  
Her joy is in her MP3 hymns,  
A bridge to the Lord it serves,  
Filtering softly through her damaged hearing nerves.

Her smiles through her goofy teeth  
Is enough to compensate for her lack of language.  
Even when she never calls me Mama,  
Her dimpled cheeks  
Makes her face so sweet,  
My heart melts.  
Who cares when she doesn't call me Mama?



## Guak Hwa's Story

### Caregiver to 31 years old son with Cerebral Palsy

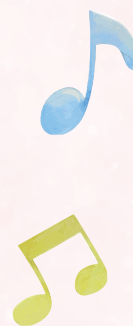
I have been taking care of my son since his birth till now.

It has been a tough journey as I had little knowledge on people with special needs, so I was caught off guarded to look after one.

I face both physical and mental challenges. As my son is fully dependent on me for his daily living needs, which included transferring him to his seat for his meal, showering and gross motor exercises. The numerous transfers had led to my constant shoulder and back ache. The intentional or unintentional looks and comments from passers-by when my son is out in the community adds on to my stress.

With the close collaboration with the school professionals, teachers and therapists, my son has improved a lot since he attended the school at 7 years old.

To de-stress, I will listen to my favourite playlist. To cope with the caregiving, I seek advice from family, friends or my child's school professionals if required. These help me overcome the difficult times gradually. For self-care, I will play my favourite playlist or listen to the radio while looking after my child. If time permits, I will make some of my favourite desserts to encourage myself.



My family members and friends have supported me. I also gained closed friendship with other parents, in CPAS, whose children are of special needs. Together, we support each other on this journey of caregiving.

Do not underestimate your child's capability. There may be moments of surprises from your child that will amaze you as a parent.

For new caregivers, do not keep everything to yourself, seek help when needed, it takes a village to raise a child. Your family members and friends are around wanting to help you but just unsure how to do so.


Frankly speaking, it will be a tough journey, but please do not just focus on the challenges. Do not forget about the sweet and funny moments while spending time with your lovely child who is more dependent on you than anyone else.

Keep calm and carry on.



*CPAS Social Work Department  
would like to thank the  
caregivers who have shared  
their stories. Your openness  
has illuminated corners  
of experience that deserve  
recognition and appreciation.*

Whilst the information presented is considered accurate at the date of publication, changes in circumstances after the date of publication may impact the accuracy of the stories. CPAS reserves the right to amend any contents at any time, at its sole discretion, without prior notice.



**Caregivers' Journey** is  
compiled by CPAS Social Work Department and  
sponsored by ***Sai Hing Medical Hall Pte Ltd***