YES! IT'S ALL ABOUT
MAKING SINGAPORE THE MOST SPECIAL-NEEDS-AWARE COUNTRY IN THE WORLD

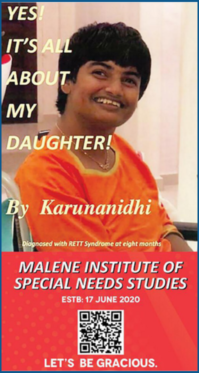
2026

VOL 2

WE FIRST

NOT FOR SALE

MAKING SINGAPORE THE MOST SPECIAL-NEEDS-AWARE COUNTRY IN THE WORLD



YES! IT'S ALL ABOUT MY DAUGHTER!

By Karunanidhi

Diagnosed with RETT Syndrome at eight months

MALENE INSTITUTE OF SPECIAL NEEDS STUDIES

ESTB: 17 JUNE 2020

LET'S BE GRACIOUS.

- Persons with special needs/caregivers must speak up.
- Government – must ensure social standing of special needs person.
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Purpose of Malene Institute of Special Needs Studies:
To look at ways to make life better for special needs persons.

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Published Jul 14, 2021

MORE THAN 1,600 PEOPLE WITH DISABILITIES HIRED UNDER JOBS GROWTH INCENTIVE SCHEME

Service staff wrapping burgers at The Social Kitchen's Jurong Bird Park branch on July 14, 2021. Ms Jessica Szeto (right), who has Down syndrome, was hired last November. ST PHOTO: KEVIN LIM

SINGAPORE - More than 1,600 people with disabilities have been hired under the Jobs Growth Incentive (JGI) scheme as at February this year, including 40 per cent who are aged 40 and older.

About 60 per cent of these hires were not holding a job at the point when they were employed under the scheme, with more than half in this group having been out of work for more than six months.

The JGI scheme, which saw $1 billion set aside as wage support, was introduced in August last year to spur firms to hire more locals.

The Ministry of Manpower on Wednesday (July 14) said that food services, environmental services and wholesale trade were the top hiring sectors, collectively accounting for slightly more than 40 per cent of JGI-supported hires of people with disabilities.

From March 1 this year, the ministry said those hiring workers aged 40 and above, people with disabilities or former offenders can receive a co-payment of up to 50 per cent of the first $6,000 of the worker's gross monthly income for up to 18 months.

One employer that has benefited from the JGI scheme is The Social Kitchen, a social enterprise that hires individuals from disadvantaged communities. It has six outlets.

Ms Jessica Szeto, who has Down syndrome, was hired in November last year to work in the company's Jurong Bird Park branch as a service staff member. It is her first full-time job.

Her duties involve packing food products to be delivered to customers.

The 30-year-old said: "(The job) has been very good. I'm very happy to do packing and serving. I was nervous at the start, but I met a lot of friends on the job and they taught me."

Ms Szeto, who attended special education schools such as Rainbow Centre Margaret Drive School, will receive further training at The Social Kitchen to progress in her career.

Ms Avelyn Lee, co-founder and director at The Social Kitchen, said the team will be giving Ms Szeto time to build up her confidence before letting her try out new roles, including taking orders online and even eventually becoming a supervisor.

"Generally, persons with disabilities, single mums and matured workers, when they join, they are a bit nervous simply because of their level of confidence.

"But (Ms Szeto) has opened up a lot since she started work. For us, the challenge is how to shorten this runway for them and not compromise their confidence," said Ms Lee.

Published Mar 05, 2022

INTERNATIONAL WOMEN'S DAY: BOSSES, COLLEAGUES RALLIED AROUND HER WHEN HER SON WAS FOUND TO HAVE AUTISM

Ms Serene Chew credits her bosses and colleagues for being empathetic and giving her time off for visits to doctors and therapy sessions for her a utistic son. PHOTO: SERENE CHEW

SINGAPORE - Ms Serene Chew's toddler stopped eating during the pandemic. At first, she thought it was because he missed their helper, who left Singapore for family reasons in August 2020.

Her son refused to be cared for by their new helper. He rejected meals lovingly prepared by her husband and drank only milk. The desperate parents scrambled to find anything that he was willing to eat - waffles, but only from a certain bakery. Eggs, but only sous vide. Now four, his diet is mainly bread-based, but again, only one type of bread.

They visited several doctors and specialists, but could not find closure. "They kept telling us that my son looks fine,"she recalls.

She began noticing that her toddler, whom she declines to name, would line things up in orderly rows in the fridge. He began vomiting whenever he experienced “big emotions”, whether positive or negative.

Just getting him out of the house was an unpredictable affair as he would vomit on his shoes or uniform, leaving his frustrated parents rushing to clean him up before they could go to work.

He had a good relationship with his grandparents, but refused their care, leaving Ms Chew’s husband, Jasper, as the main caregiver. They also have a daughter aged 11.

It was only in the middle of last year that they found out their son has high-functioning autism.

Ms Chew, 32, pauses to compose her feelings, then continues: “It was overwhelming. There was a lot of guilt, there were a lot of emotions. There was a lot of complexity that I just couldn’t wrap my head around.”

At the same time, her work at DBS was a “crazy period” as her department supports the bank in carrying out Covid-19 safety measures, which were in constant flux.

The assistant vice-president of corporate real estate strategy and administration credits her bosses and colleagues for being empathetic and giving her time off for visits to doctors and therapy sessions for her son.

She has been working in hybrid mode since early 2020, before the circuit breaker.

“My boss and colleagues are the ones who keep reminding me, ‘Serene, you’re human, you need to take time off, I got it covered’,” says the self-confessed workaholic, who is in a high potential programme at the bank.
Such is the camaraderie at work that she feels comfortable venting about challenges and celebrating her son’s small wins with them. “I can tell from their actions that they have been listening intently,” she says.
She was touched to receive marine creature-themed toys during gift exchanges as her son is obsessed with marine life.

Her colleagues engage him on the topic whenever he appears onscreen during online work meetings.
Ms Chew says she is not worried about family life affecting her career progression. “I’m in a good place with a very good employer who cares for my growth,” she says.

As much as her workplace has embraced her situation, she wishes that society would embrace her son for his uniqueness. Far too often, well-meaning people have told her he will “grow out of it”, even though there is no cure for autism.

She speaks excitedly about how she has learnt to communicate better because he does not comprehend social cues. “I realise the beauty of the world through his eyes.”

Published Mar 13, 2023

MORE CAMPAIGNS NEEDED TO RAISE AWARENESS OF DISABILITY RIGHTS

I empathise with Paralympic swimmer Sophie Soon over her experience at a cafe where she was told to sit outside with her guide dog (Paralympic swimmer Sophie Soon in stand-off over guide dog at Rocky Master outlet in Hougang, March 10).

Food establishments should not be allowed to deny indoor seating to visually impaired people with guide dogs, given that they are permitted entry by law and allowed in restaurants by the Islamic Religious Council of Singapore. Guide dogs are not the same as pet dogs. They are specially selected, undergo extensive training, and are trained to act appropriately in public spaces. If you do not disturb a guide dog, it will not disturb you.

Published Mar 09, 2023

PARALYMPIC SWIMMER SOPHIE SOON IN STAND-OFF OVER GUIDE DOG AT ROCKY MASTER OUTLET IN HOUGANG

SINGAPORE – Paralympic swimmer Sophie Soon was involved in a confrontation with a Rocky Master employee when she patronised the cafe at the Hougang 1 mall on Wednesday night, accompanied by her guide dog and her mother.
In a video taken by Ms Soon and posted on Facebook, the female employee was seen speaking on the phone before telling Ms Soon – who is visually impaired – and her mother to sit outside its premises with the guide dog.

Ms Soon's mother then asked the woman why they were being discriminated against, adding that guide dogs are allowed in restaurants by Muis, or the Islamic Religious Council of Singapore, and the Ministry of Sustainability and the Environment.

Paralympic swimmer Sophie Soon with her guide dog, Orinda.
ST FILE PHOTO

Asked what would happen if Ms Soon posted the video, the woman in the clip said: “Police report.”

“This happens practically every time I visit a new restaurant, which is a few times a week,” the 25-year-old told The Straits Times. Her guide dog, Orinda, has been with her since January 2022.

“It’s always the same when I go to a restaurant I haven’t been to before, where the staff on the ground have to check with management, and then I have to end up waiting 10 to 15 minutes.”

But this time, there was a half-hour delay before Ms Soon and her mother were seated.

Ms Soon claimed they were given three conditions by the employee in the video for remaining in the restaurant: The dog must be leashed, it must not be fed, and customers must not complain about the dog.

“As said many times before, guide dogs are allowed by law into all restaurant establishments, including halal establishments, as supported by Muis,” Ms Soon wrote in the caption accompanying the video.

In Singapore, guide dogs wear a yellow harness with text indicating that they are working dogs.

Guide dogs are approved and allowed in halal-certified premises, according to a Muis advisory.

The Housing Board and the National Parks Board's Animal and Veterinary Service allow guide dogs to live in HDB flats. The National Environment Agency and the Singapore Food Agency also allow guide dogs in restaurants, foodcourts and cafes. "How many more times do guide dog users have to be discriminated (against) before businesses finally educate themselves on the guide dog laws in Singapore?" Ms Soon wrote in the video caption.

In an Instagram post on Wednesday, Rocky Master said it does not discriminate against any diner.

"However, we are mindful to be considerate towards other diners who might not be comfortable with certain dining environments," the statement said. "Hence, we ask that guide dogs be leashed... and preferably be seated at (the) outdoor seating area where possible."

Rocky Master then said that the employee in question "may not be very experienced in handling such situations", and that she checked with her superior before making any decision.

"Even under the circumstances of being filmed, she and the rest of the team maintained their composure and did their best to accommodate and fulfil your requests," the statement added.

"We understand from our outlet manager that the staff (member) was traumatised due to the incident. We have since reached out to our staff member to express our care and concern."

This is not the first time Ms Soon has had to address concerns by members of the public about her guide dog.
In November 2022, she uploaded a TikTok clip to address a Stomp story that quoted a passenger on an MRT train saying that she was worried Ms Soon's dog might suddenly attack her and her baby, who was in a pram.

In the video, Ms Soon explained that guide dogs spend the first two years of their lives undergoing intensive training, including many tests and socialising.

She added that the dogs have to undergo a further three to four weeks of training with their handler before being allowed into the majority of public spaces.

"The only two spaces they're legally not allowed in are restaurant kitchens and surgery rooms," she said.
Ms Soon told ST that as a person with a disability, having a guide dog allows her to do the same things as an able-bodied person.

"They empower us so much to be able to live an independent life," she said, referring to such dogs.

"When people say 'go to another restaurant', that's not the point... The law supports us fully to be in there."
She added: "At the end of the day, just like everyone else, I need to eat dinner... I have a life to live."

Published Apr 30, 2023

TEEN WHO TOOK HER LIFE AT TOP BRITISH SCHOOL ‘HYPER-FIXATED’ ON HER FIRST-EVER DETENTION, SAYS DAD

Caitlyn Scott-Lee studied in various schools in Singapore when her father was working and teaching here from 2016 to 2020. PHOTO: FAMILY HANDOUT

A teen with autism took her own life a day before she was set to serve her first detention at a top boarding school in Britain, according to her father, a senior executive at HSBC who is now trying to raise public awareness about what led his daughter down a dark path.

Caitlyn Scott-Lee was found dead in a wooded area near a playing field at Wycombe Abbey School in High Wycombe, Buckinghamshire, on April 21. She was only 16.

She has studied in various schools in Singapore when her father, Mr Jonathan Scott-Lee, was working and teaching here from 2016 to 2020.Mr Scott-Lee, who now works at HSBC’s Toronto office, told The Sunday Times in London that Caitlyn wrote a final note in her diary expressing her despair at having to serve a two-hour “headmistress’ detention” at her school.

She wrote in her diary that she ran

Caitlyn Scott-Lee studied in various schools in Singapore when her father was working and teaching here from 2016 to 2020. PHOTO: FAMILY HANDOUT

away from a school trip to Eton College in March as a "cry out for help".

"I hope this is my last diary entry," she wrote on April 20. "I want to kill myself tomorrow."

Caitlyn, who was set to take her General Certificate of Secondary Education or GCSE soon, was reprimanded in March after vodka and a tattoo kit were found in her locker before the school holidays.

Mr Scott-Lee, 41, who has two younger daughters, said his daughter was "mortified to receive a detention".

"To some of us, it is a badge of honour, sitting in a room for two hours to work," he said. "But Caitlyn seemed hyper-fixated on the concept of a detention," he added. "And it seems she was determined to do anything she could to avoid it."

Caitlyn was reportedly so upset that she ran away from the choral event at Eton on March 21, and even asked her housemistress that she be suspended – a heavier penalty – instead of being put on two hours of detention.

BEING ‘NEURODIVERSE’

Mr Scott-Lee told The Sunday Times that those with autism like his daughter “tend to think of the world in binary terms”.

“It can be difficult (for them) to differentiate between two extremes,” he said.

Mr Scott-Lee said he hopes his daughter’s death will spark a national conversation in Britain about “neurodiversity”.

Such a conversation – and he is asking Prime Minister Rishi Sunak to take it on – can allow high-performing schools like Wycombe Abbey, which charges £44,000 (S$74,000) a year in tuition, to better take care of its neurodiverse students.Mr Scott-Lee wrote about neurodiversity in his 2022 essay for HSBC, and described one of his duties at HSBC as that of a “neurodiversity ambassador”.

He said in the essay that he himself had been diagnosed with attention deficit hyperactivity disorder. Wycombe Abbey, established in 1896, regularly ranks among the top girls’ schools in Britain. It has about 650 students aged 11 to 18.

Mr Scott-Lee said he did not believe, as others had alleged following his daughter’s death, that Wycombe Abbey was a “hothouse”, one that piled pressure on and pushed Caitlyn to the edge. This was “simplistic”, he said.

AUTISM IS A GIFT

In a tribute to their daughter on Friday, Mr Scott-Lee and his wife Tara, an accounts officer for mental health charity Mind, said Caitlyn was “gifted with autism” and “had a particular passion for the theatre, arts, music and the environment”. Mr Scott-Lee’s profile on LinkedIn said he worked for Standard Chartered in Singapore as head of data, technology, operations and outsourcing compliance, from 2016 to 2020.

Simultaneously, he was an adjunct senior research fellow at the National University of Singapore from 2018 to 2020. Caitlyn spent time in various schools in Singapore, Mr and Mrs Scott-Lee said in an article they wrote about Wycombe Abbey two years ago, but that she “has always had an affinity for the UK, and she had it in her mind to really want to go to a boarding school”.

After 2020, Mr Scott-Lee landed a job with HSBC and relocated his family to Hong Kong. Wycombe Abbey has said safeguarding its students is its “highest priority”. In an e-mail to parents of students in Caitlyn’s cohort, headmistress Jo Duncan said: “They are a close year group and, as you will understand, they are very shocked and upset. “It is an extremely difficult time for everyone and we will do our utmost to provide the additional pastoral care the girls will need.”

Published Jul 15, 2024

ADULTS WITH AUTISM: WILL SUPPORTED LIVING IN THE COMMUNITY BE THE ANSWER?

Ms Sharon Lee with her son Lucas Tan, who has autism, at the St Andrew's day activity centre in Siglap.
ST PHOTO: SHINTARO TAY

SINGAPORE - Executive coach Sharon Lee, 52, is concerned about where her son, 27-year-old Lucas Tan, will live in the future.

Mr Tan, who has autism, lives with his parents and has been attending a day activity centre in Siglap since 2019.

It is his mother's hope that he will live with one of her siblings when she is no longer around. If they are unable to care for him, she may have to arrange to put him in St Andrew's Adult Home, a residential home designed and built for adults with autism.

However, she noted, there are more options overseas for individuals on the autism spectrum. "In countries like the United Kingdom, adults with autism

Mr Lucas Tan, 27, lives with his parents and has been attending a day activity centre in Siglap since 2019. ST PHOTO: SHINTARO TAY

it is developing a residential living programme for such individuals. It will share more details in due time.

Mr Bernard Chew, who is chief executive of St Andrew's Autism Centre, said a different model of care could involve two to three adults with autism living together in a Housing Board flat.

have the option of supported living in the community,"

Ms Lee said. "I feel this could work if the individual has some degree of independence, but it also needs a community to assist and intervene when necessary."

In Singapore, service providers are similarly beginning to think about how care for this group of adults might evolve to solve the issue of their living arrangements as they age, especially after their caregivers are gone.

For instance, the Autism Resource Centre – which provides a wide range of services, such as early intervention, student enrichment and Pathlight School for individuals with autism – told The Straits Times

Trained support staff could be deployed to such homes, and those with more severe needs could get more generous staffing ratios and round-the-clock support.

People who are able to secure employment can continue to contribute to the community through paid or even voluntary work, he added, while others can access different community facilities and live dignified and meaningful lives.

Mr Chew said it may not be helpful to just continue building more of the same facilities that already exist, including St Andrew's Adult Home (Sengkang). This is part of St Andrew's Autism Centre, which also runs a special education school and two day activity centres.

Instead, it is important to examine the fundamental question of what service model can allow adults with autism to age with dignity and meaning, he said.

“As more adults with autism graduate from special education and mainstream schools, and their caregivers also start to age, there is a need to be looking further ahead to re-envision what kind of life an adult with autism should be living in a truly inclusive society,” Mr Chew said.

About 7,000 adults with autism aged 18 and above are known to the Ministry of Social and Family Development (MSF) and disability agency SG Enable, as they have applied for or enrolled in disability support schemes or programmes.

The overall number of people with autism in Singapore is not known, as there are those who remain undiagnosed or who have not subscribed to any services or initiatives.

When students with autism turn 18 and graduate from special education schools, they face what industry professionals call the “post-18 cliff effect”, where services drop off and they find limited support to cater to their needs. Some may move to one of 11 MSF-funded adult disability homes for long-term residential care.

Dr Eunice Tan, head of special education at the Singapore University of Social Sciences’ S R Nathan School of Human Development, said adults with milder needs should be able to adapt and adjust to living in the community with some support. This includes living in HDB flats with proper care staff involved.

Those with higher support needs should have options so that they do not have to live in institutions too, added Dr Tan, who has an adult son with autism.

“Many parts of the world, like Canada, are no longer on an institution model. It is about inclusion and being part of the community by participating in activities, regardless of how challenged a person is,” she said.

She is adamant that her son will not be placed in institutions such as homes for adults with disabilities, as she fears his quality of life will be impacted negatively.

“It is at the back of many parents’ minds how to provide the best possible life for the adult child once they are unable to take care of them or when they pass on,” Dr Tan said.

Published Jul 21, 2024

THE SCIENTIST WHO WANTS TO HEAL THROUGH FOOD

Dr Shen Yiru, 47, Founder of GentleFoods which produces meals which are not only appropriately textured and flavourful but also nutritionally complete. ST PHOTO: BRIAN TEO

Dr Shen Yiru is mighty chuffed with the new home of The Gentle Group. Located in an industrial building in Admiralty Road, the 7,600 sq ft space is a massive upgrade from the social enterprise's previous 360 sq ft base in Geylang.

The new facility, occupied since May, houses a central kitchen which can produce at least 2,000 meals a day for people with dysphagia, or swallowing difficulties. It also has a training centre where caregivers and staff of nursing homes can learn how to prepare flavourful and nutritious food for seniors and discharged patients.

Dr Shen, 47, has come a long way from 2019 when she left a stable job as assistant vice-president of A*ccelerate, the commercialisation arm of the Agency for Science, Technology and Research (A*Star) to chase a dream. With a PhD in neuroscience, specialising in physiology, she wanted to make a real impact in healthcare and improve the lives of patients.

It was a dream inspired by her late maternal grandmother, who struggled with dementia before her death more than 20 years ago. The illness stole her memory and cognitive abilities, and also left her with swallowing difficulties.

“She was a very sharp and knowledgeable woman who loved to eat and travel, but after she got dementia, she forgot everything, including how to swallow or chew,” Dr Shen recalls.

Attempts to feed her grandmother pureed food often resulted in frustration, as nothing tasted familiar to her. That experience stayed with Dr Shen a long time and finally inspired her to start GentleFoods, which boasts an extensive menu of popular Asian meals – from chicken rice to chicken satay – which are not just appropriately textured and flavourful but also nutritionally complete. As far as possible, the soft foods are moulded to resemble their original forms, to look more appetising

Besides the elderly, dysphagia can affect people who have had a stroke, neurological disorders such as Parkinson’s disease and multiple sclerosis, and disease or injury to the head, neck, throat or oesophagus. Estimates suggest that approximately 8 per cent of the world’s population – or nearly 600 million people – have dysphagia.

“We want to bring life back through eating, we want to help patients recover through food,” Dr Shen says.

Restlessness had led the feisty elder of two children, born to a cargo supervisor and a hotel housekeeping staff member, to become a scientist. “I need to find challenges and create things,” she says, adding that she “cannot stand boring things”.

She obtained her doctorate from the National University of Singapore, where her thesis was on the cochlea and how hair cells affect hearing as a person ages.

Over the next 15 years, she worked in sales for major multinationals like healthcare conglomerate Sysmex Asia Pacific and life science and research company Thermo Fisher Scientific. During this time, she married a civil servant and became a mother to two, now aged 12 and 16.

Although well-paying, the regional roles required her to travel often. “I thought I shouldn’t be such an uninvolved mother,” she says.

So, she joined A*Star, where her job was to leverage technologies developed in its laboratories and transform them into market-ready products. There was, however, a conviction that she should start looking at food as medicine.

"Food is comforting and brings people together. But in hospitals, people often don't touch their food. Meal times are supposed to be happy times. If you are sick and you don't eat well, you don't recover," says Dr Shen, adding that her grandmother's dysphagia prompted her to read and do a lot of research on the subject.

"I asked myself if this problem will be a big one with the silver tsunami," she says, referring to Singapore's rapidly ageing population. By 2030, one in four Singaporeans will be aged 65 and above, compared with one in five now, and one in 10 in 2010.

When she broached the idea behind GentleFoods to her parents and some friends, they thought she was crazy. "But I told myself, I want to do something that is meaningful and impacts people's lives directly – and that I should do it while I was still young," says Dr Shen, who poured in a chunk of her savings to incorporate GentleFoods in 2017. She left A*Star in 2019 to run it after raising $500,000 from investors.

There was another reason why she believed she was on the right track: the International Dysphagia Diet Standardisation Initiative framework that was published in 2017. This standardised the terminology used to describe food textures and drink thickness: Drinks fall between Levels 0 and 4 for runny to thick liquids, while foods range from Levels 3 (liquidised foods) to 7 (easy to chew, normal food).

"There are standards for medical devices but not in the food space except for this," the scientist in Dr Shen stresses.

"Let's say a patient with dysphagia goes to Thailand for medical treatment. If medical staff know that he's a Level 4, they'd know exactly what sort of texture they could serve him."

She started GentleFoods with a lean team comprising a sales manager, an administrator and a food technologist, all working out of a shared working space in Geylang. The first year was spent mainly on product development, which saw her diving into countless recipe and chemistry books.

Their initial offerings were limited to just a few items such as fish curry and chicken rice, packed in bento boxes that they publicised and sold on their e-commerce platform. Then – "whether lucky or unlucky" – Covid-19 happened. The lockdown brought their B2B operations to a halt.

"During this time, we approached corporations to sponsor the donation of our bento boxes to nursing homes. People were stuck there because of the lockdown, so these boxes brought a lot of joy. It was like a test bed for our products and people started to know us."

The feedback was more than encouraging. Patients liked that the pureed meals were tasty, well-shaped and colourful – in short, appetising. Focusing on local Asian flavours is a key focus and strategy. “It’s what our customers are familiar with.”

GentleFood’s menu has expanded to more than 50 items and now includes items such as nasi lemak, mango lassi, chwee kueh and kuih salat. A bakery specialising in soft bread and bakes is in the pipeline.

For public health science doctorate student Siti Hazirah Mohamad, 36, GentleFoods has been a godsend. She is the caregiver to her father, 63, who suffered a stroke 14 years ago and has been on a feeding tube for more than a decade.

Blending food for him when he regained the ability to eat was an often frustrating exercise in trial and error. Finding GentleFoods a few years ago took a load off her mind, because it was safe and convenient, she says. More importantly, her father enjoyed eating again.

“The first time I saw him eat with relish, I cried. He’s not eating purely for sustenance now, he’s eating for pleasure.”

The journey has not been easy for Dr Shen, who went without a salary for three years. But her determination is now paying off. The team has grown to 18 members. Online sales are rising, and nursing homes and hospitals such as St Luke’s are now ordering meals for their patients.

They now serve about 1,500 meals a day, freshly prepared and then frozen for easy steaming and serving.

Dr Shen is grateful for partners such as DBS, which believed in her vision. In 2021, she applied for and received the DBS Foundation Social Enterprise Grant, which enabled her to hire more staff and scale production. In July 2024, Heritas Capital’s Asia Impact First Fund, launched in 2023 with DBS Foundation and other partners, invested $2 million in The Gentle Group.

DBS has also helped with networking, relevant contacts and media outreach. Through DBS, Dr Shen participated in a six-month programme in Taiwan, exploring potential partnerships with manufacturers there.

Demand for GentleCare, the group’s service arm offering home visits, consultations and workshops, is also growing. Her goal, she declares, is “globalisation”.

“Singapore is well known for being multicultural and famous for its great food,” she says.

“I hope to do my bit and bring GentleFoods to the world.”

Published Jul 17, 2024

WHEN MUM'S GONE: HOW SHE EQUIPS HER LESS ABLE CHILD TO LIVE INDEPENDENTLY

A joint effort by DBS Foundation and SG Enable is addressing the gap in financial and digital literacy skills training for persons with disabilities

Since Mr Sayfullah was a teen, Madam Fadillah has taught him how to order at fast-food restaurants and cafes using his iPad. Today, he can do so confidently.
PHOTO: THARM SOOK WAI

One fear constantly weighs on Madam Siti Fadillah's mind: When she's no longer around, "what will happen to my Sayfullah?"

Mr Muhammad Sayfullah is her 21-year-old special needs son. And Madam Fadillah, 46, is his mother and main caregiver.

Mr Sayfullah was diagnosed with quadriplegic cerebral palsy when he was nine months old. The condition affects his muscle control, motor skills and speech.

He is wheelchair-bound and uses an assistive technology tool, an iPad, to communicate. The eldest of three children, Mr Sayfullah has a sister, 19, and a brother, 11.

Madam Fadillah knew she needed to have a difficult conversation with her son about the future. With a heavy heart, she asked: “What if Mummy is no longer around?” It was met with raw, tearful distress from Mr Sayfullah, who was 10 years old then.

He had relied on his mother for all daily activities. “He thought that I would be caring for him to no end,” says Madam Fadillah. But in that moment, it suddenly hit him that one day, she might be gone. Madam Fadillah’s concerns are common among caregivers of special needs individuals, highlighting a gap in support for this community.

In focus groups held by SG Enable, 80 per cent of persons with disabilities surveyed said that digital and financial literacy, which are essential for daily living, are not covered in any existing training programmes. About 450 participants joined SG Enable’s focus groups held between 2022 to 2023. They included persons with disabilities, caregivers, social service agencies, institutes of higher learning and employers. To address this gap, DBS Foundation and SG Enable, the focal agency for disability and inclusion, entered into a three-year partnership to equip 7,000 persons with disabilities and caregivers with these crucial skills. The partnership is the first of its kind, says Ms May Koh, director of Enabling Academy at SG Enable, “in which a corporate partners the disability sector to upskill persons with disabilities on a national scale”.

Mr Sayfullah uses an assistive technology tool, an iPad, to communicate.
PHOTO: THARM SOOK WAI

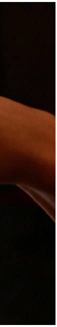
Fadillah’s concerns are common among caregivers of special needs individuals, highlighting a gap in support for this community.

NEEDS, WANTS, AND FUN

The learning curriculum by DBS Foundation and SG Enable, of up to 30 modules, will be rolled out in 2025. Pilot workshops are underway.

Mr Sayfullah and Madam Fadillah were invited to the first pilot workshop last November, together with three other persons with disabilities and their caregivers.

Mr Sayfullah was initially reluctant to attend the financial literacy workshop, his mother shares. “I don’t like mathematics,” he quips.



The family, together with their two-year-old cat Cheetah, lives in a two-room rental flat in Eunos. In the living room, with walls painted a cheery yellow, there is a hospital bed with side rails and adjustable sections. It’s where Mr Sayfullah sleeps each night.

Madam Fadillah affectionately teases her son (“Why are you shy today, Sayfullah?”) throughout the conversation. Mr Sayfullah listens quietly; when a topic interests him, such as shopping centres and food, he chimes in using his iPad.

It took some persuasion before Mr Sayfullah agreed to attend the 1.5-hour workshop held at Enabling Village in Lengkok Bahru. The session was facilitated by DBS employee volunteers. The topic: needs and wants.

By the end of the workshop, “Sayfullah had so much fun, he didn’t want to leave”, Madam Fadillah says.

Mr Sayfullah was also keen to contribute to the discussion. When a facilitator said gadgets are a “want”, he disagreed and pointed to his iPad. “He understands that it’s a need for him,” Madam Fadillah adds.

Acknowledging the importance of financial literacy for Mr Sayfullah, she also hopes that future sessions can cover other crucial life skills, such as cashless payments and how to calculate discounts at supermarkets.

HE WANTS TO EMPOWER

Growing up with Madam Fadillah’s love and encouragement, Mr Sayfullah not only dreams big – he wants to contribute to the society.

His aspiration? To open a “technology-powered cafe” manned by persons with disabilities.

The idea took root after his mother brought him to the APSN Cafe for All in the Kembangan-Chai Chee Community Hub in August 2022.

The cafe is run by trainees from The Association for Persons with Special Needs (APSN), who have mild intellectual disabilities.

“(The staff) were intrigued by Sayfullah and his iPad,” says Madam Fadillah. At the same time, “we were intrigued by their ability to cook and serve us food that (looks and tastes just as good as other restaurants)”.

On the way back, Mr Sayfullah turned to his mother: “I want to employ people like them.”

Madam Fadillah was initially puzzled: “For what?”

That's when Mr Sayfullah clarified excitedly that he wanted to open a cafe selling "coffee and his favourite apple crumble". He envisioned a smart kitchen and a place where people with disabilities could work and thrive.

Madam Fadillah gives him her wholehearted support. She has never doubted his potential to achieve more. "I'm always challenging him to learn new things, (and in return), I've learnt so much from him as well."

While her fears for his future haven't entirely disappeared, her perspective has shifted. Mr Sayfullah's dream gives her hope – that even when she's no longer around, he's able to craft a fulfilling, independent life for himself.

SKILLS AND SUPPORT FOR THE LESS ABLE

Last November, DBS Foundation partnered SG Enable to strengthen support and skills training for persons with disabilities.

Set up by the Ministry of Social and Family Development in 2013, SG Enable is the focal agency for disability and inclusion.

The initiative's aim: To enable persons with disabilities to live more independently, especially in today's fast-changing world.

DBS Foundation is contributing $1 million to the initiative. The bank will provide subject matter expertise in financial and digital literacy skills, and mobilise its employee volunteers as workshop facilitators.

It's also timely and necessary. As the world becomes more digital, persons with disabilities are vulnerable to being left behind, says Ms May Koh, director of Enabling Academy at SG Enable. For example, they may be "more vulnerable to online scams and cyber attacks".

The learning curriculum will include topics like needs and wants, and scenario planning to ensure the long-term financial security of persons with disabilities in the event of their caregiver's death.

"With an ageing population, declining birth rates and shrinking household sizes in Singapore, the disability landscape will face challenges such as care planning for persons with disabilities who may outlive their caregivers, and increased caregiving loads for smaller families," says Ms Koh.

In Singapore, 40 per cent of adults with disabilities will be 65 years old or older in 2030, according to the Enabling Masterplan 2030, which maps out the country's vision for creating a more inclusive society.

Giving time and heart work

The initiative resonates deeply with Ms Kavitha Sivadoss, one of the DBS volunteers who facilitated the pilot financial literacy workshop.

She is vice-president of DBS' investment and trading technology division, and mother of a special needs child.

Ms Kavitha Sivadoss is mother to a special needs child herself, and an active volunteer with DBS Foundation initiatives. PHOTO: DBS FOUNDATION

Her younger son, 18, was diagnosed with autism and attention deficit hyperactivity disorder (ADHD) when he was three. She has an older son aged 20.

The workshop was "memorable", says Ms Sivadoss, as it was her first experience working directly with persons with disabilities.

Ms Sivadoss became an active volunteer with DBS Foundation initiatives shortly after joining the bank in 2022. Last year, she accumulated 114 volunteering hours, equivalent to about 14 working days. The bank's over 14,000 employees in Singapore get two days of volunteering leave per year.

They are encouraged to volunteer their time and skills to support the community.

"I used to spend my entire weekend caring for my younger son," says Ms Sivadoss. But now that he has moved to India to live with her husband, who's working there, "I decided that volunteering was a good way to make use of my time".

This was produced in partnership with DBS Foundation.

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‘WE THOUGHT HE WAS JUST NAUGHTY’: OVER 1 IN 100 CHILDREN IN SINGAPORE HAVE AUTISM

Ms Hellen Yong with her husband and children. Ms Yong’s eight-year-old daughter was diagnosed with autism at the age of four.
PHOTO: COURTESY OF HELLEN YONG

SINGAPORE - More than one in 100 children at the age of 18 months here have autism – the age when kids can be screened for the condition.

A local study published in 2023 by the National University Hospital (NUH) and National University Polyclinics found that among 5,336 children aged around 18 months, the prevalence of autism here was 1.1 per cent, or roughly just over one in 100 children.

The prevalence of autism – a neuro-developmental condition – here was estimated at one in 150 children in 2016.

Overall, the number of children aged six and below with developmental needs, which include speech and language delay and behavioural problems, has increased by 32 per cent from 5,300 in 2019, to 7,000 in 2023.

Among those diagnosed with such needs, about 20 per cent have autism. The Ministry of Health (MOH) released these figures in response to queries from The Straits Times, providing the latest data from the Child Development Programme at KK Women's and Children's Hospital (KKH) and NUH.

Doctors say the rise largely stems from increased awareness and screening.

An MOH spokesman said: "The overall better early detection can be attributed to various efforts to encourage parents to take their children for Childhood Developmental Screening at appropriate touchpoints, so that children who may need interventions are identified early."

For instance, developmental checks on personal-social and motor skills, as well as language, are conducted together with the recommended childhood vaccinations to make it more convenient for families.

Associate Professor Lourdes Mary Daniel, head and senior consultant at the Department of Child Development at KKH, said there is improved awareness of autism symptoms.

Other factors associated with increased likelihood of autism include mothers being over 40 years of age at the child's birth, and birth prematurity of less than 35 weeks of gestation, or birth weight under 2.5kg, she said.

Prof Daniel said antenatal screening during pregnancy can help identify maternal, placental and fetal conditions and environmental risk factors for developmental concerns in the foetus. These include birth defects and structural abnormalities, as well as blood flow to the fetal brain.

Dr Aishworiya Ramkumar, senior consultant at NUH's Khoo Teck Puat – National University Children's Medical Institute, said excessive screen time also has cognitive implications.

A 2024 NUH study found that children referred for developmental, behavioural or emotional issues had been exposed to more than two hours of screen time a day on average when they were aged two and under, against international guidelines, which advise no screen time for children in this group.

Excessive screen use among infants and toddlers can lead to attention, language and social skills difficulties as well as aggressive behaviour in later childhood, said paediatricians.

IS SINGAPORE READY TO SUPPORT THE GROWING NUMBERS?

Currently, there are 25 special education schools for students aged seven to 18 in Singapore.

Three more will be set up by 2032 to meet the growing demand of students with moderate needs who have autism and can access the national curriculum, said the Ministry of Education (MOE). Pathlight School and St Andrew's Mission School are currently the only government-funded schools serving this group.

The upcoming schools are: Pathlight School 2 run by Autism Resource Centre (Singapore) (ARC) in Tampines in 2025; a new school by Methodist Welfare Services in partnership with Anglo-Chinese School, to start operations in 2026 and to relocate to Tengah in 2031; and Pathlight School 3 in Punggol in 2032.

When completed, the upcoming schools will provide about 1,500 primary and 1,050 post-primary school places, MOE said.

Parents told ST that getting an autism diagnosis allowed them to get their children into schools to get the support needed.

Pre-school teachers told consultant Hellen Yong that her daughter could not interact well with other children and was more difficult to handle. For instance, she became so attached to the playground swing that she would refuse to return to class.

Ms Yong, 42, wasted no time in taking her daughter to the doctor, where she was diagnosed with autism at the age of four. The girl, now eight, is a happy Primary 2 pupil at Pathlight School. She was given the option to transfer to a mainstream school, but Ms Yong decided that the support from Pathlight's teachers and peers there would suit her daughter better.

"I'm thankful we didn't delay treatment. Now she's doing well, and I'm happy seeing her improvement every day," she said.

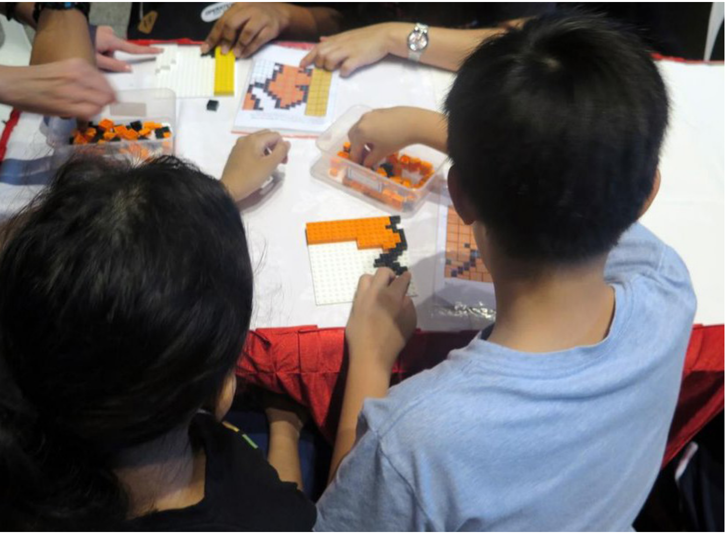
GETTING ADEQUATE SUPPORT

Rachel (not her real name) said a polyclinic doctor referred her son to KKH for review after finding that he could not say "mummy" at his two-year-old milestone check. The boy was diagnosed with autism at the age of four.

"I was in denial. At first, I felt guilty. What have I done wrong that my son is like this? Then it turned to anger, then regret, and the negative feelings went on," said the 44-year-old housewife who declined to be named.

"Some parents are stronger, and they accepted their fate earlier. For me, it took quite a while."

Her son, now six and still non-verbal, did not attend pre-school as no centre wanted to take him in. Instead, he attended six hours a week of the Early Childhood Development Agency's Early Intervention Programme for Infants and Children (Eipic), which supports



The number of kids aged six and below with developmental needs has increased by 32 per cent from 2019 to 2023.
PHOTO: ST FILE

children with developmental needs in a group setting.

"For Level 3 autism, which is considered severe, this is definitely not enough. My son's improvement is not obvious compared with high-functioning kids," said Rachel.

Dr Nah Yong Hwee, an educational psychologist who specialises in the detection of autism, noted that Eipic also has to support other children without autism and faces manpower and space constraints. Hence, some children with autism may not get the intensive support needed, with general research recommending at least 10 hours of intervention a week.

Another parent, Mr Dylan Lau, 43, said his son showed a deep interest in fans and trains from a young age, and would have meltdowns triggered by loud sounds from the blender, vacuum cleaner and hair clippers.

"As he is our firstborn, we thought he was just a bit naughty," he said. It was only later when one of his son's taekwondo classmates suggested that his son might have attention deficit hyperactivity disorder that Mr Lau took him to KKH.

There, the boy was diagnosed with moderate autism, and a doctor promptly wrote a letter for his primary school studies to be deferred and for him to enrol in Eipic.

"It was a relief as we finally understood why he was the way he was, and we could now help him improve himself. Getting that diagnosis was a big turning point for us," said Mr Lau.

The Eipic classes improved the boy's social skills, and he even discovered a talent for music. His parents signed him up for piano classes, which helped him regulate himself better.

They also engaged a private child psychologist to help him adapt and interact with his peers.

Mr Lau, a software engineer, took a year off work to take his son to playgrounds every day to practise interacting with others.

Now 11, the boy is a Primary 4 pupil at Pathlight.

"I wouldn't say he is 'cured', but he doesn't wander off as much now," Mr Lau said. "It is a regret on our side that we didn't catch this earlier. We missed out on those precious years of development."

THE 'POST-18 CLIFF' EFFECT

ARC president Denise Phua lauded the increase in attention and resources for students up to the age of 18, but said: "Beyond that age is a significant gap in resource matching and the needs in learning, living and working.

"The direction is clear that we need to plug the gaps in the space of adult disability, especially autism, because of the spectrum of severity and needs, including comorbidities such as intellectual challenges."

Dr Sim Zi Lin, psychologist and programme director at ARC, said some priority areas include planning for adults with autism after the death of their caregivers, as well as developing residential and work options for them.

"Children on the autism spectrum grow to become adults on the autism spectrum," she said.

Ms Phua said: "Families, of course, must play an active role, but the Government, businesses and the rest of the community must come strongly into the picture... We as a society must take action, and urgently."

Published Oct 20, 2024

SHE THOUGHT HER DAUGHTER'S SWEET FRAGRANCE WAS A BLESSING; IT TURNED OUT TO BE A DEADLY CONDITION

Medical Mysteries is a series that spotlights rare diseases or unusual conditions

Elvia Lim, five, with brother Elvis, eight, and mother Madam Felicia Tan, 36.
ST PHOTO: ONG WEE JIN

SINGAPORE – Sugar and spice, and all things nice – that was what Madam Felicia Tan thought little girls were made of when her daughter Elvia Lim was born in 2019.

"My firstborn, a boy, cried throughout the night. Elvia was different. She smelled as sweet as maple syrup. She hardly cried and always slept," the 36-year-old housewife said, telling The Straits Times that she was blessed to have a baby girl who was naturally this way.

What Madam Tan did not know was that her daughter's sweet fragrance hid a sinister underlying condition.

But she noticed that Elvia, at a week old, was not drinking enough breast milk. Concerned, she contacted Thomson Medical, where she had given birth.

"I thought the issue was mine, so I made an appointment with the lactation consultant and I brought her along," Madam Tan said.

The lactation nurse told the parents to rush the newborn to the emergency department at KK Women's and Children's Hospital.

Elvia was taken to the intensive care unit after she was diagnosed with maple syrup urine disease (MSUD).

She was then 14 days old.

In this rare inherited genetic metabolic disorder, the body cannot process certain amino acids, especially leucine, causing a harmful build-up of substances in the blood and urine. Amino acids are formed when protein in food is digested.

A sudden, severe spike in leucine in the blood can cause brain swelling and damage, seizures, long-term intellectual disability, and even death when left untreated.

Chronic elevations in leucine, even at moderate levels, can predispose individuals to brain damage.

The severity of MSUD ranges from mild or intermittent to severe, the most common form.

A baby with the severe disease may not survive more than a few weeks without treatment.

Leucine is an essential amino acid needed for the healing of skin and bones, and increased muscle growth and lean body mass. It is found in all protein-containing foods, so MSUD is treated with a strict, lifelong diet that restricts protein intake.

When Elvia was first admitted to hospital, her skin was mottled.

"I was told her toxic amino acid levels were more than 3,600 and that she should have been critical, but she was able to breathe on her own and there was no fever. After they brought the levels down, she was allowed home," Madam Tan said.

Several months later, she and her husband Andy Lim learnt that liver transplantation was an effective long-term treatment for the disease, and decided to pursue this option to give their daughter a shot at a better future.

MSUD affects an estimated one in 180,000 babies born.

"In Singapore, we expect one child in every five to six years to have this condition, and, as far as I know, we already had three in the last 18 years," said Associate Professor Denise Goh from the National University Hospital

Newborn screening is optional, and Madam Tan did not opt for it.

Elvia Lim at five days old. She smelled sweet like maple syrup and hardly cried, her mother said.
PHOTO: FELICIA TAN

Elvia Lim at 20 days old, after her discharge from the intensive care unit. She was one of three babies diagnosed with maple syrup urine disease in Singapore in the past 18 years.
PHOTO: FELICIA TAN

(NUH), who was part of the team that managed Elvia before and after her transplant surgery.

In some cases, the babies are very ill and exhibit symptoms, leading doctors to suspect the disease.

But with advanced newborn screening, many cases are now picked up before the babies become severely sick, explained Prof Goh, who heads the genetics and metabolism division in the department of paediatrics at NUH.

But at three months old, Elvia was back in hospital as she had stopped drinking and swallowing milk.
She was found to have laryngomalacia, a common disorder in babies where the tissues above the voice box soften and fall over the airway.

“The doctors’ attention was on her MSUD so her laryngomalacia was missed,” her mother said. “She had to have a gastrostomy tube inserted to feed fluid and nutrients directly to her stomach.”

Elvia spent three months in the

hospital, and had to continue the tube-feeding at home.

"She had to be fed every two hours and her stomach capacity then was only 100ml," her mother said.
It was a very trying period, and Madam Tan said she was racked with guilt, wondering if it was the right decision to have the gastrostomy tube inserted.

Her daughter's skin was breaking down due to her nutritional deficiency, and she had to be admitted to hospital each time the tube leaked or when the baby was having a fever.

It was during this time that Elvia's parents learnt about the promising results liver transplantation could have for MSUD.

"It was by chance that surgeons in the United States discovered that liver transplant was an effective cure for MSUD," Prof Goh explained. "A girl with MSUD required a liver transplant after she was given too much vitamin A, and it turned out to be an effective cure."

The Lims moved their baby to NUH, where Madam Tan sought out Adjunct Associate Professor Vidyadhar Mali, surgical director of the paediatric kidney and liver transplantation programmes.

"I knew of Dr Mali through an article about a previous case of MSUD, so we went to the emergency room at NUH and demanded to see him," Madam Tan recalled.

It was an eight-month wait before a suitable living donor was found.
"Usually we would ask one of the parents to donate, but in Elvia's situation, part of the genes that caused her MSUD came from the parents, which meant that we could not take any of their livers," Prof Mali explained.

"In such situations, we either put the child on the national waiting list or we look to the National Organ Transplant Unit for an altruistic anonymous living donor."

The team that carried out the transplant and managed Elvia Lim's MSUD: (from left) Adjunct Associate Professor Vidyadhar Mali, Associate Professor Denise Goh, and Assistant Professor S. Venkatesh Karthik.
ST PHOTO: ONG WEE JIN

Madam Felicia Tan with her five-year-old daughter Elvia Lim. The girl now has a voracious appetite, earning her the nickname "little hungry monster".
ST PHOTO: ONG WEE JIN

Prof Mali said: "Things were happening in parallel. Elvia had come to us with feeding issues, and we were sorting that out. At the same time, tests were being carried out to ensure the donor was suitable and healthy."

Prof Goh said Elvia's MSUD made the transplant more challenging.

To ensure that she would be strong enough for the operation, Elvia was taken off gastrostomy tube-feeding the day before the transplant and fed a special nutritional formula intravenously.

This provided her little body with the nutrients, including special amino acids that did not cause her MSUD to worsen.

The formula was specially prepared by hospital pharmacists with special amino acids sourced from around the world.

The surgery was finally carried out in 2022, when Elvia was three.

Elvia received a third of the donor's liver in an operation that took about 10 hours.

"The liver needed to work immediately, otherwise Elvia would develop a metabolic crisis," said Prof Mali.

Elvia's pre- and post-surgery nutritional health was taken care of by Assistant Professor S. Venkatesh Karthik, a senior consultant with the paediatric liver transplantation programme.

Fondly dubbed Elvia's "foster father" by her parents and her other doctors, he will be managing her until she is 21.

Prof Karthik said children like Elvia would need lifelong immunosuppression medication to prevent the body from rejecting the organ.

They would have to avoid raw foods and probiotics and observe basic hygiene to avoid infections.
The first year after the transplant would be the most challenging, as this is typically when rejection happens, he added.

Two years on, Elvia now attends pre-school, plays with her classmates and – other than avoiding probiotic foods like yoghurt, sourdough bread and Yakult or Vitagen – eats like any other voracious child.

"This means that her liver is doing well and it is playing catch-up, catch-up with all the nutrients the body needs. Being very active, it is not surprising that Elvia is hungrier than before," Prof Mali said.

Elvia is no longer the sweet-smelling angel her mother thought she was. "Instead, her teachers have given her a new nickname – the little hungry monster," Madam Tan said, laughing.

Published Nov 30, 2024

BOILS, BLISTERS ON BABY'S SKIN POINT TO GENETIC DISORDER

Medical Mysteries is a series that spotlights rare diseases or unusual conditions

SINGAPORE – Leora Lim was born in 2021, bringing joy and hope to her parents.

But three days after her birth, rashes appeared on her delicate skin, which quickly turned into boils and blisters. Seeking answers, her parents took her to a paediatrician, who then referred them to a dermatologist.

"After several visits and tests, we received the diagnosis: incontinentia pigmenti (IP). We were told it's a rare genetic condition," said Leora's mother, Ms Hazel Ng.

Leora Lim, three, has incontinentia pigmenti, a rare X-linked dominant genetic condition. ST PHOTO: AZMI ATHNI

"When we heard those words, it felt like our world had shifted."

The 38-year-old physical education teacher learnt that IP could be hereditary, so she underwent DNA testing together with her daughter.

"While I tested negative, Leora's results confirmed (what is known as) a deletion on her X chromosome. It was heartbreaking. As her parents, we felt overwhelmed with questions, fears and the weight of the unknown," she told The Straits Times.

IP is a rare X chromosome-linked genetic disorder that affects the skin,

Three days after Leora Lim was born, rashes appeared on her delicate skin, which quickly turned into boils and blisters. PHOTO: COURTESY OF MS HAZEL NG hair, teeth, nails, eyes, brain and central nervous system.

Associated problems of IP include delayed development, intellectual disability, seizures and other neurological problems.

Associate Professor Mark Koh, who heads the department of dermatology at KK Women's and Children's Hospital (KKH), said: "About 10 per cent may have neurological issues like fits, seizures. They may have developmental delays...

"I would say most of our patients, about 90 per cent, do pretty well neurologically."

The gene can be passed from mother to daughter, but that was not the case with Leora.

Instead, her condition was the result of mutations in the IKBKG gene, also called Nemo, that is located in the X chromosome.

"Every time a cell splits, the DNA needs to be replicated; otherwise, there is not enough DNA to split into two cells," Dr Koh told ST.

"So when a cell splits, the two need to 're-spell' everything, that is, copy everything out again. It is not photocopying but more like manually typing, so errors occur."

He added that most male foetuses with the disease do not survive to childbirth. Globally, one in 50,000 newborns suffers from the condition, and KKH sees about two or three new cases every year.

Associate Professor Mark Koh (standing), head and senior consultant for the department of dermatology at KK Women's and Children's Hospital, is the doctor managing Leora.
ST PHOTO: AZMI ATHNI

All such cases in Singapore are referred to KKH.

"It is almost exclusively in girls. When they are born, the condition presents with the streaks of blisters. They usually occur in the first few weeks of life before turning into wart-like lesions, making the skin a good diagnostic criterion," Dr Koh said.

These lesions, which can appear on 20 per cent to 50 per cent of the body, develop into grey or brown patches which fade with age, becoming lighter than the skin colour, Dr Koh added.

There is no specific treatment or cure for IP, and Dr Koh said the main thing is to prevent secondary bacterial infection of skin lesions and to monitor closely the development of related problems in areas such as the eyes and teeth.

The first few months of Leora’s life were filled with challenges.

Her mother said her skin demanded constant care – cleaning, medicating and soothing of the blisters.

“Each one left behind scars, which we now call her tiny battle marks,” Ms Ng said, adding that it was and still is a delicate balance between letting Leora enjoy her childhood and safeguarding her health.

“We avoided swimming for her entire first year and introduced it only cautiously after that, starting with 10-minute sessions and gradually increasing the time,” she said.

“Even now, we have to carefully manage her time in the pool; anything beyond 45 minutes triggers dryness and eczema.”

Other than the skin, the eye suffers the most common side effect.
Dr Koh said: “(Girls with IP) can get new blood vessels forming at the back of the eye. These vessels are very fragile, so they break easily and bleed into the retina. The girls can go blind.

“About 40 per cent to 50 per cent of our patients have this eye issue.

So we always refer them to the eye doctors, the ophthalmologists, and they undergo (laser treatment) very early to treat these blood vessels.”At just two months old, Leora underwent her first angiography, an imaging test to view the blood vessels in her retina, and it revealed a leaking blood vessel in her left eye. It needed immediate laser treatment to prevent retinal detachment.

Leora showing her teeth which are peg-shaped due to her incontinentia pigmenti.
ST PHOTO: AZMI ATHNI

By the time she was 16 months old, another angiography revealed a constricted blood vessel in her right eye, leading to a second laser procedure.

Said Ms Ng: “For two years, Leora

Ms Hazel Ng (left), 38, a physical education teacher, worries how she is going to explain the condition to daughter Leora when she is older. ST PHOTO: AZMI ATHNI

had eye checks every three months and they were some of the hardest moments for us, the parents. "To keep her still, she had to be swaddled and restrained. She was wailing while I held her and the nurse secured her head.

"When she turned three, her surgeon gave us the news we had been praying for – her eyes were developing well, and she would not be needing further laser treatments."

Then there was the issue of her teeth. Like all IP patients, they were peg-shaped, and her dental visits began at 18 months.

"Although her teeth grew more slowly than those of her peers, she was able to eat normally. Some of her teeth are peg-shaped, but for now, it is more of an aesthetic concern. Her smile, however, is perfect to us," Ms Ng said, adding that it is Leora's smile that continues to give her parents strength.

Dr Koh said after her adult teeth develop, she will be sent for reconstructive surgery. Through all of this, Leora, now three, showed true grit, said Ms Ng.

She was playful and referred to herself as "Baby Leora" when ST visited her home.

"Leora has taught us more than we could ever imagine. She may be only three, but she has shown us the true meaning of courage and resilience," her mother said.

However, Ms Ng continues to worry about her daughter's future. "We need to break the news about her condition to her when she is much older.

"She will need to understand that her condition might carry a 50 per cent probability of being passed to her own child.

"It's a difficult truth, one that we will keep tucked away until the time is right."

For now, the parents are focusing on nurturing her confidence and appreciating their daughter a day at a time.

Published Dec 02, 2024

DECLINE IN POSITIVE ATTITUDES TOWARDS PEOPLE WITH DISABILITIES AT THE WORKPLACE: MSF REPORT

The proportion of respondents who had positive attitudes toward PWDs in the workplace decreased from 59.6 per cent in 2019 to 50.6 per cent in 2023.
ST PHOTO: WONG YANG

SINGAPORE - Positive sentiments towards people with disabilities (PWDs) have declined in Singapore and this was mainly due to a dip in attitudes at the workplace.

In 2023, 68.9 per cent of people here held a positive attitude towards PWDs. This was a fall of nearly 8 percentage points from the 76.8 per cent in 2019.

In particular, the proportion of respondents who had positive attitudes towards PWDs at the workplace decreased from 59.6 per cent in 2019 to 50.6 per cent in 2023, a survey by the National Council of Social Service showed.

dbEnable representatives from Deutsche Bank receiving the Enabling Mark (Platinum) from SG Enable in October. PHOTO: DEUTSCHE BANK

About 2,000 Singapore residents without disabilities were polled on how they viewed PWDs in areas such as education, employment and public access.

Results from the Public Attitudes Study, which was conducted in 2019 and 2023, were highlighted in the first Disability Trends Report released by the Ministry of Social and Family Development (MSF) on Dec 2.

The change in attitudes comes amid ongoing efforts to increase the employment rate of PWDs in Singapore to 40 per cent by 2030. An estimated 4,500 more such individuals are expected to have jobs by that year. The report provides an overview of key trends relating to PWDs and their caregivers in areas such as inclusive employment, quality of life, caregiving support and public attitudes.

The study on public attitudes also showed a decrease in the proportions of respondents who reported positive attitudes towards those with sensory disabilities like visual impairment and deafness (80.9 per cent to 72 per cent). A larger drop was seen for less visible disabilities like intellectual disability (68.4 per cent to 57.3 per cent) and autism (69.9 per cent to 56.2 per cent) over the same period. In contrast, positive attitudes towards those with physical disability remained stable.

Respondents were asked to rate how they felt on statements such as “I find it stressful to be co-workers with persons with disabilities” and “Employers should make changes to the job and/ or office environment so that persons with disabilities can be hired”.

An MSF spokeswoman said that while the study did not identify specific reasons, it found public attitudes were associated with frequency of contact with PWDs. “Respondents who had contact with PWDs at least twice in the past year reported significantly more positive attitudes, compared with those who had no contact.”

Mr Alvin Teo, head of relationship and transaction management coverage in

Singapore at Deutsche Bank, worked with a colleague with a disability for the first time in 2021. The colleague, who joined his team in the same year, has brittle bone disease, a genetic disorder that results in bones that break easily.

Mr Teo said he felt unsure of whether and when to help his colleague at the start. But he grew more comfortable with his colleague over time, with the bank organising talks to inform employees about working with people with various disabilities.

Mr Raily Tissera, regional HR business partner for corporate bank for Deutsche Bank, said the bank's dbEnable Work Placement Internship Programme, which supports students with disabilities to gain professional experience in the bank, has been running for 10 years. Out of 50 to 60 undergraduate interns so far, around five to 10 have become permanent employees, he added.

Speaking about his colleague, Mr Teo said: "He's a confident man and open about his condition, and he can joke around. Then it becomes more light-hearted and not so serious."

He recounted an incident where his colleague took it with humour when Mr Teo forgot to help him down the escalator on the way to lunch and left him at the top of the escalator. He said the team invites the colleague to join its activities, even a division bowling outing where he ate with the team members and cheered them on from the sidelines.

Mr Teo acknowledged that employees with and without disabilities might vie for opportunities in a competitive work environment, but added: "I believe any organisation can bring in diversity hires to meet a quota, but no organisation would promote a diversity hire if he doesn't have the ability.

"You have to start raising his pay, giving him higher bonuses. At the end of the day, the organisation is also there to make a profit."

Mr Teo said he has learnt from his disabled colleague to be more empathetic. "People with disabilities are more thoughtful to other people. People without disabilities like me, we take the little things in life for granted and we stop sparing a thought for other people. Through my colleague, I feel I've become a better person over time."

Dr Eunice Tan, head of the Singapore University of Social Sciences' (SUSS) special education programme, said many companies have jumped on the bandwagon in the Government's push for inclusive hiring, but there is no buy-in from managers and rank-and-file employees.

Dr Tan, who is overseeing an inclusive hiring project at SUSS, said there should be training for employees at all levels on how to work alongside a person with autism, for instance, as well as on the challenges they face and strengths. “Many times, service staff can say mean and unkind words to the PWDs, which can lead to emotional distress and self-esteem issues,” she added.

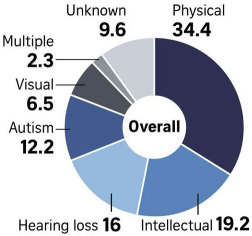
Ms Tay Soong Kiang, assistant chief executive of disability charity SPD, said stressful workplace environments and a lack of understanding of accommodations needed for PWDs may contribute to the decline in positive attitudes towards them.

“As a nation still in the early stages of our inclusion journey, it is clear that more efforts are needed to raise awareness, foster understanding, and promote acceptance of individuals with disabilities and the challenges they face in the workplace.”

MOST COMMON DISABILITIES IN SINGAPORE

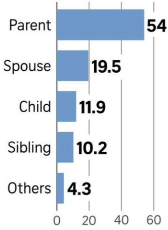
There were around 45,000 people with disabilities aged 19 and above known to the Government.

People with disabilities known to the Government (%)



NOTE: Figures are as at December 2023. “Unknown” refers to cases where data is unavailable.

Caregivers’ relationship to people with disabilities %



NOTE: “Others” includes caregivers who are grandparents, guardians or friends.

Percentages do not add up to 100 due to rounding off.

Sources: MINISTRY OF SOCIAL AND FAMILY DEVELOPMENT, DISABILITY AND INCLUSION PANEL STUDY 2022, NATIONAL COUNCIL OF SOCIAL SERVICE STRAITS TIMES GRAPHICS

Published Dec 15, 2024

TREE OF HOPE: CAMPAIGN TO RAISE FUNDS FOR THOSE WITH RARE DISEASES

With a “Wizard of Oz” theme, the 2024 campaign aims to “light up the Tree of Hope in the Land of Hope”.
PHOTO: RARE DISEASE FUND/FACEBOOK

SINGAPORE – People with rare diseases often need expensive medicines to lead normal lives. To help them, the Rare Disease Fund (RDF) has brought back its Tree of Hope fund-raiser for the second year.

With the theme of “Wizard of Oz”, the 2024 campaign aims to “light up the Tree of Hope in the Land of Hope”. The RDF is managed by the KKH Health Fund, which is part of the SingHealth Fund and is supported by the Ministry of Health.

From now till Dec 25, the public can support the Tree of Hope by donating at www.giving.sg/rare-disease-fund.

Every dollar donated by the public will be matched with $3 by the Government.

Donors get a tax deduction of 2.5 times the donated amount.

About 3,000 people in Singapore have been diagnosed with rare diseases such as bile acid synthesis disorder, Gaucher disease and Pompe disease, and around 700 of them are children. Most cases are diagnosed in childhood and require lifelong medication.

Eleven Singaporeans – or about 0.37 per cent of the 3,000 patients – have received help from the RDF since it was started in 2019.

Health Minister Ong Ye Kung said in March that most patients with rare diseases are able to get financial help from schemes such as MediSave and MediShield Life, and subsidies. He said in a parliamentary response that those who struggle to pay their bills can also apply for MediFund through the public health institutions.

Only a small percentage of patients may need additional financial assistance, and the RDF was set up to support high-cost medication for this group, he added.

“Given the limited size of the RDF, funding support is focused on treatments for rare conditions that are life-threatening and where the treatment is effective in extending the patient’s lifespan,” he said.

Besides donating to the Tree of Hope, the public can show their support through tasks such as reposting content about the campaign on social media, taking part in the RDF’s social media activities that involve answering questions about rare diseases, and watching the stories of beneficiaries featured on the RDF’s social media channels (@rarediseasefundsingapore).

More information is also available at https://www.kkh.com.sg/giving/Documents/Rare-Disease-Fund/index.html

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Published Sep 15, 2024

CAN DEMENTIA OR STROKE PATIENTS AGE WELL? YES, IF MINDSETS CHANGE

We need to rethink our concept of successful ageing and accept and embrace declining faculties.

The recent suicide of acclaimed Chinese novelist Chiung Yao sparked an outpouring of grief, as well as discussions on the care that older people receive. Still looking hale and hearty at the time of her demise, she chose death to take control of her life, as she did not want to endure a slow decline and the prospect of becoming frail and dependent.

Some supported her choice to take matters into her own hands while others bemoaned her decision and regretted that she had seemingly failed to consider the sentiments of those who loved her. One might also speculate on whether she suffered from untreated depression after her husband’s death, possibly impairing her judgment and mental clarity as she took that fateful decision.

We need to rethink our concept of successful ageing and accept and embrace declining faculties, says the writer.
ST PHOTO: GIN TAY

Amid the buzz around successful and active ageing today, would one consider Chiung Yao to have aged successfully? She was, after all, poised and spritely at 86 and ultimately remained in control of her life even unto death. One could equally hold the other view that ageing well should encompass the ability to adapt positively and roll with the punches that accompany ageing. Clearly, it would be contentious to portray her as a role model for other seniors, lest they entertain thoughts of taking their own lives too. It is concerning that in some parts of the world, some people are documenting in their advance care plans the desire for euthanasia should they succumb to a particular state of dementia, frailty or dependency in the future.

Given the hackneyed negative stereotypes surrounding ageing, it would be pertinent to reframe ageing more positively. The idea of successful and active ageing was conceived to depict seniors harnessing their inherent value for their own good and the good of society at large. That said, successful ageing can also be construed as an oxymoron because ageing is predictably accompanied by decline and eventual death. Although personal responsibility has a part to play in determining how we age, many suffer from age-related diseases due to factors beyond their control. Is successful ageing then beyond the reach of those stricken by chronic disabling illnesses such as dementia, stroke or organ failure?

There is no denying the importance of ageing actively with the goals of avoiding or minimising disease, and maximising physical, mental and social engagement. However, the relentless pursuit of successful ageing may inadvertently engender a cultish mindset that adores the traits that convey wellness and vitality, and values seniors merely by their instrumental worth. Herein lies the slippery slope that could lead us from seeking active ageing to being antiageing, eschewing ageing as if it were a bane, with attempts to forestall or reverse it.

EMBRACING THE DECLINE

We would do well to rethink the concept of successful ageing. It needs to embrace decline and appreciate the worth of seniors beyond utility and material value. Seniors are worth much more than their personal attributes. As enunciated by William Thomas, a thought leader in eldercare, “elders are the glue that bind us together”. This holds true even if seniors become frail and lose their utilitarian worth, as can be seen in patriarchal figures in families and the society at large.

Ageing comes with certain losses and we have to accept that. Seniors who fight the inevitable consequences of ageing may find ultimately themselves at the losing end and become despondent. Conversely, those who are able to transcend the losses through acceptance, lowered self-expectations and finding new meaning, gain integrity.

Instead of fostering paradigms of active ageing in physical, economic or social terms, ageing with a greater sense of coherence involves seniors looking back on their life and gaining fresh insights from the past to make sense of the present, and finding hope for the future. Such resilient seniors can maintain their sense of well-being despite the ravages of ageing.
A concrete way to help seniors find closure and completeness in their lives is to initiate life-story reminiscence groups, possibly in active ageing or daycare centres, community clubs or religious settings. Here I would commend a particular form of telling a life story with emphasis on meaning, known as spiritual reminiscence.

Spiritual reminiscence can identify meaning associated with joy, sadness, anger, guilt, or regret. Exploring these issues helps seniors find new meaning, purpose and hope by reframing life experiences, coming to a new understanding, acceptance and transcendence. A study of a six-week spiritual reminiscence intervention in Hong Kong provided evidence of positive outcomes among seniors, in terms of hope, life satisfaction and well-being, even as they suffered from dementia.

Dignity therapy is another well-established intervention to uphold a person’s dignity by helping them record the meaningful aspects of their lives to leave a lasting legacy that can benefit their loved ones and others in the future. It can bring about inner fulfilment and engender new optimism in transcending personal needs by promoting the interests and welfare of subsequent generations. Dignity therapy as well as spiritual reminiscence can conceivably be implemented on a more systemic level through health and social care agencies, as well as organisations that promote positive ageing such as the Centre for Seniors and Council for Third Age.

DIGNITY DESPITE DEMENTIA

For seniors stricken by dementia, as the illness progressively impairs cognitive faculties and threatens the attributes that define their identities as people, maintaining integrity needs to draw on the relational. This experiential dimension subsists in relationships expressed in human bonding and connectedness, transcending the material world. Author Christine Bryden, a public figure living with dementia, once famously said, "A person is a person through others… we know the feeling but don't know the plot. Your smile, your laugh and your touch are what we will connect with… We're still in here, in emotion and spirit, if only you could find us".

Seniors with advanced cognitive deficits may no longer be able to form critical interests – things that provide meaning and purpose, which are engendered by a rational mind. However, they can continue to have experiential interests that are sensory-focused. Therefore, unlike active ageing which is beyond the reach of the physically and cognitively frail, a more expansive notion of ageing well embraces the whole person, inclusive of both critical and experiential interests. It is premised on the ethos that humans are embodied beings and hence vulnerable, yet remain relational and experiential, and thereby retain integrity through interconnectedness. To rate critical aspects above experiential interests implies we hold the belief that some lives are lesser than others because of their diminished mental faculties. How could we then call ourselves a caring society?

Chiung Yao, known for her public endorsement of euthanasia, had her supporters echoing "your life is your own decision". The choice to live and die on one's wishes is emblematic of a certain hubris. It echoes expressive individualism in which one is who one chooses to be. Modern freedom, which espouses doing whatever one wishes, is at odds with the traditional notion of freedom – doing what one ought to do. When faced with frail and vulnerable seniors, would not the objective good be to care with love and kindness than to bless euthanasia, which is implicitly underpinned by egotism and unbridled individualism?

As a novelist who often concluded her stories with romanticised sentimentality, Chiung Yao chose to write the final chapter of her life on her own terms. In contrast, one might express freedom in the choice to surrender one's will, acknowledging that some things are beyond our control. Spiritual writer Ronald Rolheiser writes: "In this life, all symphonies remain unfinished. Our deep longings are never really satisfied." By this, he intuits a transcendent order beyond this life that can finally satiate our human desire for meaning, justice and love. Perhaps, it is in this higher order and frame of reference that we can hope to understand the meaning behind the seemingly senseless pain and suffering that accompany ageing, illness and loss.

We might do well to age with courage and patience in that hope.

Philip Yap is the chairman of Dementia Singapore.

HELPLINES MENTAL WELL-BEING

- Institute of Mental Health's Mental Health Helpline: 6389-2222 (24 hours)
- Samaritans of Singapore: 1-767 (24 hours) / 9151-1767 (24 hours CareText via WhatsApp)
- Singapore Association for Mental Health: 1800-283-7019
- Silver Ribbon Singapore: 6386-1928
- Tinkle Friend: 1800-274-4788
- Chat, Centre of Excellence for Youth Mental Health: 6493-6500/1
- Women's Helpline (Aware): 1800-777-5555 (weekdays, 10am to 6pm)

COUNSELLING

- Touchline (Counselling): 1800-377-2252
- Touch Care Line (for caregivers): 6804-6555
- Care Corner Counselling Centre: 6353-1180
- Counselling and Care Centre: 6536-6366
- We Care Community Services: 3165-8017

ONLINE RESOURCES

- mindline.sg
- eC2.sg
- www.tinklefriend.sg
- www.chat.mentalhealth.sg
- carey.carecorner.org.sg (for those aged 13 to 25)
- limitless.sg/talk (for those aged 12 to 25)

Published Feb 09, 2025

MEDICAL MYSTERIES: THE STUDENT WHO IS SLOWLY 'TURNING INTO STONE'

Medical Mysteries is a series that spotlights rare diseases or unusual conditions.

Student Raphaella Gautama is currently the only person in Singapore with a condition called fibrodysplasia ossificans progressiva, which limits her movement.
ST PHOTO: AZMI ATHNI

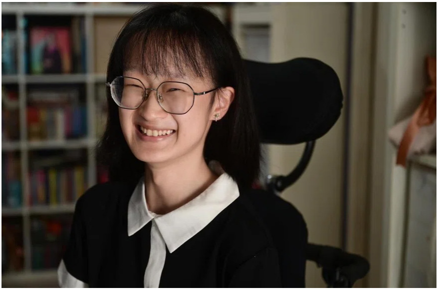
SINGAPORE – NTU student Raphaella Gautama is slowly "turning into stone".;

The 20-year-old wheelchair user has a very rare condition called fibrodysplasia ossificans progressiva (FOP), which causes her muscle and tissue to gradually change into bone, causing stiffness and limiting her movement.

It all started with a fall in the bus when Ms Gautama was 13.

"It felt like I had sprained my ankle, but when the hospital took an X-ray, there was weird bone growth. The doctors did not know what it was or how to diagnose it," she said.

She told The Straits Times that she was in limbo for two years as doctors tried to find out what was causing muscle and tissue in her lower back and hip to fuse and turn into bone, causing pain and stiffness.



Ms Gautama is determined not to let her health condition define her or "scuttle my ambition to do well in life". ST PHOTO: AZMI ATHNI

"We made regular trips to the hospital for blood tests, scans and X-rays, but each time, we returned home disappointed. There were no answers," said Ms Gautama, who is pursuing a bachelor's degree in linguistics and multilingual studies.

Then, in June 2019, she was referred to Associate Professor Angeline Lai, who suspected the teen had FOP and "convinced my mother to send me for genetic testing".

She tested positive for FOP. The condition is also known as stone man disease or Munchmeyer disease.

Prof Lai, a senior consultant from the Genetics Service at KK Women's and Children's Hospital (KKH), told ST that FOP is "an ultra-rare genetic condition". The body makes extra bones where bone should not form, including in muscles, tendons, ligaments and other connective tissue.

FOP is caused by a mutation in a gene that plays a role in the formation of the skeleton in the embryo. It arises due to errors during DNA replication.

"Bridges of extra bone may form across the joints and lead to stiffness, locking and permanent immobility. In a sense, people with FOP develop an extra skeleton. The extra bone formation usually starts within the first two decades, with most having an onset before the age of 10," she said, adding that the unusual appearance of the big toes at birth could also serve as an early clue.

"Inflamed and sometimes painful swellings that look like tumours appear typically in the shoulder and back areas. Because of the rarity of FOP, these swellings may be thought to be cancer or benign tumours. The swellings eventually resolve but they leave behind a new piece of bone," Prof Lai said.

"If a child with FOP has a fall, the area of injury may develop into an inflamed lump and later into new bone formation," she added.

The condition affects approximately one in a million people worldwide and the median life expectancy is 56 years, based on available literature.

Dr Lena Das, a senior doctor with the rheumatology and immunology service at KKH, said: "Anecdotally, some patients live productive lives into their seventh decade, despite severe disability. Death often results from breathing failure."
Ms Gautama is currently the only person with the condition in Singapore, which might be why it took two years before she was diagnosed.

"Raphaella is only the second patient with FOP whom I have seen, with the first being almost 20 years ago," Prof Lai said.
"(When she first came) to KKH's Rheumatology and Immunology Service in February 2019, Raphaella had multiple areas of pain and joint limitation. The MRI showed inflammation and joint damage that is associated with arthritis... She was referred to our genetics team that made a conclusive diagnosis after a few months," said Dr Lena, who is managing Ms Gautama's condition.

Dr Lena was referring to flare-ups – the unpredictable episodes of soft tissue swelling, and pain that reduces movement, stiffness and warmth that people living with FOP experience.
Flare-up symptoms usually resolve within eight weeks, although this may take longer if the back or hips are affected.

Dr Lena said while FOP is a disease of connective tissues, such as ligaments, tendons and skeletal muscles, "certain muscles like the diaphragm and tongue seemed protected. (The heart) muscle and smooth muscles are not involved".
There is no cure for FOP and its management is supportive.

Unfortunately, palovarotene, the only US Food and Drug Administration-approved drug therapy developed primarily for the treatment of FOP, is not available in Singapore.

"What we aim for is to minimise the flares and control new flares when they happen. Raphaella is on Gleevec, (used primarily for treating cancers), which serves the same purpose.

"While literature is sparse, this drug has been used to good effect in FOP patients and has so far worked quite well on Raphaella," Dr Lena said.

TAKING THE CONDITION IN STRIDE

Instead of feeling despondent after she was diagnosed, Ms Gautama said she and her parents "actually felt a sense of relief".

"We finally knew what I had and were able to deal with it instead of going to the hospital only to be disappointed each time with the non-diagnoses," she said.
Ms Gautama was determined not to let her condition define her or "scuttle my ambition to do well in life".

"I do not wish to lower my own standards just because I have more difficulties than the next person," she said.

Ms Gautama said that, at first, it was hard to explain her condition to her classmates in secondary school because in 2019, she was "still walking fine", and then in 2020,

After graduating with a diploma from Temasek Polytechnic, Ms Gautama received a scholarship to support her pursuit of a Bachelor of Arts at NTU.
ST PHOTO: AZMI ATHNI

she was using a wheelchair.
"It was easier when I went to Temasek Polytechnic. Everyone was new and we were all grappling with the new landscape. One girl there taught me a great life lesson," she said.

"I was using the socket on the floor to charge my laptop in the lecture hall. My friends had helped me with the plug earlier. At the end of the lesson, I was waiting for someone to help me unplug when this girl walked up, unplugged, and handed it to me. Then she said rather curtly, 'If you needed help, you just need to ask rather than wait for it'. I realised she was right," Ms Gautama said.

So the self-professed introvert learnt the importance of self-advocacy and discovered that she could pursue her aspirations with resilience on her own terms.

She said she does not overthink about her future and instead takes it a day at a time.

After graduating with a Diploma in Law and Management from Temasek Polytechnic, Ms Gautama received an Asia Pacific Breweries Foundation scholarship in September 2024 to support her pursuit of a Bachelor of Arts in Linguistics and Multilingual Studies at NTU.

To avoid having to commute, she stays at the student dormitory on campus. She said that during orientation, she learnt to take the campus bus or go to the cafeteria early to avoid the crowd. "Otherwise, I would need to wait for a long time and that would make me late for my lectures and tutorials...

"Many people think that because I need a motorised wheelchair, I cannot walk (at all) or care for myself. I still can. I walk very short distances within my room. And if making Maggi noodles for myself constitutes cooking, then yes, I cook too," she said with a laugh.

Correction note: In an earlier version of the story, we said that FOP is caused by a genetic mutation during the formation of the skeleton in the embryo and the repair of the skeleton following birth. Professor Angeline Lai has since clarified that FOP is caused by a mutation in a gene that plays a role in the formation of the skeleton in the embryo.

Published Mar 01, 2025

LOVE SCAM VICTIM WITH SPECIAL NEEDS WAITED IN VAIN AT TANAH MERAH FERRY TERMINAL FOR ‘GIRLFRIEND’

THK Home for Disabled @ Sembawang collaborated with the police for the first time in October 2024 to conduct a scam prevention talk.
PHOTO: THYE HUA KWAN MORAL CHARITIES

SINGAPORE – A man with an intellectual disability fell for a woman he got to know on social media and transferred more than $100 to her from his savings account.

When the woman said she was coming to Singapore to visit him, he waited for her at the Tanah Merah Ferry Terminal for half a day. But she never turned up and cut off contact with him.

Ms Gina Tan, lead social worker at SPD, a charity which helps people with disabilities, recounted this incident to The Straits Times in February to highlight how vulnerable those with special needs are to being scammed.

SPD worked with RSVP to organise an anti-scam awareness talk with the police for 20 clients and caregivers in November 2024. PHOTO: SPD

Scam victims in Singapore lost a record $1.1 billion in 2024, according to annual scam figures released by police on Feb 25. This was the first time an annual loss to scams crossed the $1 billion mark.

So far in 2025, more than 3,500 cases of scams have been reported, with victims losing more than $80.7 million. Amid the scam scourge, social service organisations said people with intellectual disabilities are especially vulnerable.

SPD, Thye Hua Kwan Moral Charities (THKMC) and Touch Community Services, which serve people with intellectual disabilities, are teaching their clients how to protect themselves against scams.

In the love scam case, Ms Tan said the scammer approached John (not his real name) on social media posing as a pretty woman. Ms Tan said: “As the relationship grew over two months, he naively thought: ‘OK, I want her to be my girlfriend’.”

Soon, John sent her money to “support” her, and wanted to marry her.

The woman claimed she was coming to Singapore, and John was adamant on going to the ferry terminal to meet her. After her no-show, she stopped contacting him.

Ms Tan said John was heartbroken but did not make a police report.
Ms Chloe Lee, the superintendent of THK Home for Disabled @ Sembawang, a home for adults with intellectual disabilities, said it is common for its clients to receive scam video calls.

Some scammers even use artificial intelligence to impersonate celebrities or police officers.

Ms Lee said it is harder for people with intellectual disabilities to process complex information, assess risks or detect deception.

She said: "Most of them would have a very trusting nature because they also desire connection with people."
Ms Ang Chiew Geok, who heads the Touch Special Needs Group, said scam cases are not common among its trainees as most of them do not have a bank account, or have withdrawal restrictions in place.

But she added: "We are more concerned about cases where persons with intellectual disabilities have physical encounters with strangers, who exploit their vulnerabilities to trick them into giving money."

Ms Ang said a police report will be made if the case involves bigger sums of money, or if the perpetrator appears to be targeting the group's trainees.
Ms Lee said the home's clients are taught to inform staff members or their caregivers if they encounter a scam.

In John's case, Ms Tan said social workers could not verify if the woman was indeed a scammer, but they tried to ask him how he knew she was sincere if he had never met her.

Ms Tan said they can counsel clients but cannot overrule their choices because people with intellectual disabilities still have decision-making capacity.

She added: "It's not right for us to say he cannot have a girlfriend... It's their right to have social relationships, it's just that it needs to be managed properly."

Working with RSVP, an organisation of senior volunteers, SPD organised an anti-scam awareness talk with the police for 20 clients and caregivers in November 2024.

In October 2024, THK Home for Disabled @ Sembawang collaborated with the police for the first time to conduct a scam prevention talk for staff and some residents. It covered online fraud, phone scams and banking security.

The home also worked with university students, who designed a pamphlet for its clients, with simple English and visuals, about identifying scam video calls.

Similarly, Touch Ubi Hostel, a residential training hostel for adults with mild intellectual disabilities, has conducted two talks with the police on topics such as scams and the dangers of disclosing personal information.
Coaches also teach Touch's trainees

about protecting their privacy on social media and managing their money responsibly.

The police told ST that between 2022 and 2024, they conducted an average of four scam prevention talks each year for people with intellectual disabilities, through social service agencies Minds and APSN, which serve individuals with special needs.

In 2024, the police also linked up with the Enabling Services Hubs to arrange talks for their clients. These talks were conducted by community policing officers, who delivered their presentations in simple English and used slides with images and straightforward text. A police spokeswoman said: "Throughout the sessions, officers carefully observed participants' body language and responses to ensure the messages were being understood." She added that police officers would also share scam prevention tips with the next of kin of people with intellectual disabilities.

SPD's Ms Tan said bank officers and the public can be on the alert for people with intellectual disabilities withdrawing money at banks.

She added: "They can be sensitive to the fact that there are people with intellectual disabilities who are vulnerable to scams, and spend a bit more time to check in on them."

Christine Tan is a journalist at The Straits Times reporting on crime, justice and social issues in Singapore.

Published Mar 26, 2025

NEGATIVE ATTITUDES HINDERING SOCIAL INTEGRATION OF PEOPLE WITH EPILEPSY

March 26 marks World Purple Day, a global initiative dedicated to raising epilepsy awareness, dispelling myths and offering support to around 50 million people living with epilepsy. Countries around the world come together on March 26 to raise awareness of epilepsy, acknowledge the bravery of those diagnosed, and stand in solidarity with all those impacted by this common and complex neurological condition.

These include some 25,000 people in Singapore affected by epilepsy, along with their loved ones, families and caregivers.

Epilepsy, which can affect anyone, is a chronic brain disease characterised by abnormal brain activity causing seizures or unusual behaviour, sensations and sometimes loss of awareness.

People with epilepsy are still subjected to stigmatisation and discrimination as a result of the misconceptions and negative attitudes that surround this often misunderstood condition. Stigmatisation leads to many people with epilepsy being unnecessarily restricted in their choice of employment, or not being able to find any.

People with epilepsy should have the same rights as others in gaining access to education, training and employment opportunities. They should be regarded as having equal value, and have talents that can be developed.

The social implications of epilepsy should not be understated. In fact, social factors are often a greater barrier to the social integration of people with epilepsy than the seizures themselves.

Published Mar 31, 2025

'THIS WORLD IS EQUALLY THEIRS': A PARENT'S CALL FOR A BETTER WORLD FOR CHILDREN WITH AUTISM

SINGAPORE - Eleven-year-old Naufal was splashing about with his younger sister Nadine in their condominium pool, occasionally mimicking the Merlion by spouting water out of his mouth.

A woman, an unfamiliar face, then approached him and told him off. Naufal responded by splashing water at her.

Pulling her brother aside, Nadine, nine, explained to the woman that her

National football captain Hariss Harun and his wife, Ms Syahirah Mohamad, said their parenting journey has been one of trial and error.
ST PHOTO: AZMI ATHNIST PHOTO: AZMI ATHNI

brother is autistic, but was met with a terse response: "It doesn't matter; he shouldn't be doing that."

In tears, she headed back home and recounted the incident to their father, national football captain Hariss Harun.

The 34-year-old player posted a video about the Feb 4 incident on Instagram later that day, urging the public to have more empathy for those with autism. In the video, he said that after

apologising to the woman, he told her that he tries his best to inculcate good values and etiquette in Naufal, but at times, this is more difficult for children with special needs.

Nonetheless, he added: "My son deserves to be out there; it is a free world. It is no different for him.

"That is why I am sharing this – to raise awareness for those with special needs. This world is equally theirs as it is ours."

'TRIAL AND ERROR'

Situations like the one Mr Hariss shared are one of the biggest fears of parents with special needs children, said Mr Chris Lim, who has two boys with autism.

He recalled a recent incident during the school holidays in March when his younger son Gabriel, 12, went to a mall with his friends.

Gabriel was playing with a ball at a shop when it bounced out the door, setting off alarms. "He freaked out and totally panicked. He wasn't sure what to do. He cried, he called me right after and I immediately rushed over," said Mr Lim, 43.

"As a parent with a child with special needs, when instances like this happen, it really scares you," said the art director at a digital agency.

Mr Chris Lim, who has two sons with autism, started volunteering at CaringSG, a non-profit organisation that supports caregivers of persons with special needs, in 2020.
PHOTO: COURTESY OF CHRIS LIM

The journey of raising children on the autism spectrum is one of "trial and error", Mr Hariss and his wife, Ms Syahirah Mohamad, and Mr Lim told The Straits Times in separate interviews.

For every new phase Naufal enters, his parents have to teach him a new set of skills, like how to socialise with his peers at school.

Naufal will soon be going through puberty, which Ms Syahirah thinks would be the toughest phase to get through.

"He has sensory needs; sometimes he doesn't like to wear his shirt to bed because he's sensitive to fabric. What if he's affected by sweating or having body odour? What if he wants to keep taking showers again and again?"
They will just have to go back to the drawing board to find out what suits him, said Mr Hariss.

Mr Lim and his wife took about a year to prepare their sons to venture out of their home by themselves when they were about 10 years old. This involved taking the boys out to perform day-to-day tasks such as buying groceries, ordering food and taking public transport.

The couple taught the boys by repeating the bus routes and tasks several times, and used notes and cards to help them internalise better. Lastly, the boys were always reminded to phone home if things went awry, such as if they missed their bus stop.

They then loosened the reins and let the boys go about independently while they shadowed them at a distance. When they finally felt comfortable, they allowed their older son, Clarence, now 14, to go out alone when he was 12.

"The younger one then said, 'Kor kor can, so why can't I?' But the first time he went out with his friends, it turned out like this," said Mr Lim, referring to the incident at the mall.

"Special needs caregiving is a bit of a minefield," he said. "You try different things; some things work, some things don't.

"But that's fine, because as parents, when we can, we let them go and when they need us, we just reassure them, 'I'm just around the corner. It's okay'."

'A MARATHON, NOT A SPRINT'

"Why me? Why us?" These questions no longer creep up on Mr Hariss and Ms Syahirah as frequently as before. Now, an emphatic declaration – "I love someone with autism" – is on Ms Syahirah's Instagram bio. On the platform, she invites questions on parenting and receives a constant barrage of them from fretful parents in return.

"A lot of them are in the (early) stage of denial. They hope that I'll reply with answers that they want to hear," she said. “I’ve gone through that – at the time when I wanted to believe that my son is normal.”

National football captain Hariss Harun and his wife, Ms Syahirah Mohamad, who said her main focus is to help their son Naufal thrive while being unique and his own person. ST PHOTO: AZMI ATHNI

To Ms Syahirah, Naufal is shy, loving and a foodie who would make a stellar food blogger, but she knows he is different.

“I have now accepted that the world will always seem odd to him, and he will always seem odd to the world,” she said. “Now, my main focus is to help him thrive while being unique and being his own person.

“When parenting most children, you need to let them fly. But for kids with special needs, you have to stand up for them and be their voice,” she said.

Mr Lim knows the early stages of denial all too well. When he learnt that his sons were autistic, he struggled to accept their diagnosis and blamed himself for it, he said. “There was a lot of unforgiving and that stopped me from moving forward for a couple of months.”

He now works on a part-time basis at CaringSG, a non-profit organisation that supports caregivers of those with special needs, as the charity’s IT and communications manager. While pouring his energy into caring for his sons, he learnt that he needed to care for himself, too.

“I always tell myself that as a caregiver, I am with my children for life,” he said. “At the end of the day, I know that they will need me, so I need to take care of myself as I take care of them.

“It’s very important to know that it’s more of a marathon than a sprint, and you have to pace yourself and not burn yourself out over this journey.”

THE VISION: A SOCIETY WITH AWARENESS AND EMPATHY

While the majority of the public are understanding, Ms Syahirah noted that the occasional unpleasant run-in with strangers does occur.

She recalled an incident when Naufal repeatedly touched a bicycle that belonged to a young neighbour in their previous condominium.

"He likes to touch things he likes," she said.

The girl complained to her father, who scolded Naufal. But Naufal, instead of getting scared or running away, continued to touch the bicycle. The girl's dad then shouted at him, and Ms Syahirah had to race over to deal with the situation.

"I apologised and said my son is a special needs child, but he shouted at me and said, 'I don't care! Just teach him some manners'."

The situation was all too familiar for Ms Denise Phua, Mayor of Central Singapore District and president of the Autism Resource Centre (Singapore). Her son, Mr Tay Jun-Yi, 30, is also autistic.

Ms Phua recalled that he was physically abused by his Chinese teacher when he was four years old as she felt he was "unresponsive" during classes. In a separate incident, a tall and burly man pushed Mr Tay, who was young at the time and unable to speak, to the floor when he thought the boy was disturbing his dog.

"I think he was not aware nor was he interested... His father and I went home distraught and sad," Ms Phua said of that episode.

"Jun-Yi is now a big and strong young man and is better able to defend himself," she added. "But the memories remain even after more than two decades."

Ms Phua, an MP for Jalan Besar GRC, said she envisions a society where every individual, regardless of ability, is respected, valued and empowered to reach their potential.

This society also embraces inclusivity and empathy, and recognises the right of everyone to have social relationships and community spaces, she added.

Referring to the confrontation between Naufal and the neighbour, she said: "In situations like these, do not be too quick to judge. Do not assume that a child's behaviour is a result of poor parenting or a lack of discipline – it could be due to the child being different and may not be within their control.

"Show empathy to both the child and the caregiver, and as an extra step, show interest to find out more about others who may be neurodiverse and different."

Mr Hariss, whose exploits on a football field are well documented but who has remained largely guarded about his family life, said he decided to put out the video because he wanted to educate people.

"I just wanted everyone to be more understanding, and society to be more empathetic and inclusive," he told ST.

"Whether you have a family member or friend with special needs, we can all always look out for one another."

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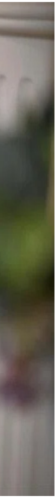
BLACK BELT IN TAEKWONDO, GRADE 8 IN PIANO: S'PORE TEEN EXCELS DESPITE CONDITION THAT LIMITS MOVEMENTS

Lai Jia Chi (centre with her parents, Mr Lai Shu Hau and Ms Liew Pui Yee.
ST PHOTO: ARIFFIN JAMAR

Lai Jia Chi has Glutaric Acidemia Type 1 (GA1), a genetic disorder detected at age three after a severe fever, despite appearing healthy initially.

GA1, if undetected, can cause brain damage; early intervention through diet control, supplements, and monitoring allows normal development, like Jia Chi's achievements in Taekwondo and piano.

Jia Chi's parents manage her condition with strict diet control and



exercises, spending $400 monthly on medication and supplements to prevent muscle weakness and brain damage. SINGAPORE – At 15, student Lai Jia Chi holds a black belt in taekwondo and is doing Grade 8 in piano – accomplishments that might not have been possible if her rare condition had not been detected early. Jia Chi has glutaric acidemia type 1 (GA1), an inherited metabolic disorder that prevents the body from properly breaking down certain amino acids. If left unmanaged, the condition will cause brain damage and movement difficulties.

She was born in 2010, when screening for metabolic and heritable diseases in newborns was already available. But her parents did not want her to have her blood taken at such a young age.

Her condition was detected when she was almost three years old, her father Lai Shu Hau told The Straits Times. "One night, she became very ill and her fever was at 41 deg C. We tried to wake her up the next morning, but she was unresponsive and her eyes were rolled back. We rushed her to a nearby paediatrician, who then called an ambulance," said the 46-year-old manager in the oil and gas industry. Jia Chi, the older of two daughters, was diagnosed with fever caused by an infection, and with a very high level of uric acid in her urine.

Still concerned, Mr Lai asked for a DNA test to be done. That was when they found out that Jia Chi had GA1.

"She was showing symptoms in the first two years of her life. She did not want to drink milk.

Neither did she want to eat meat. We just thought that she was a fussy eater, but it was her body just not wanting to have protein," Mr Lai said.

GA1 affects the body's ability to break down three types of amino acids – lysine, hydroxylysine and tryptophan – which are commonly found in protein-rich food such as meat and fish.

These amino acids must be broken down as the body cannot store them in large quantities. When the body cannot properly break down the amino acids, a toxic by-product called glutaric acid builds up.

Associate Professor Tan Ee Shien, who heads the genetics service at KK Women's and Children's Hospital, said glutaric acid can cause serious health complications, particularly affecting the brain.

She explained that the breakdown of amino acids requires an enzyme called glutaryl-CoA dehydrogenase (GCDH). Every person inherits two copies of the GCDH gene – one from each parent – which provides instructions for producing the enzyme.

Lai Jia Chi, an Integrated Programme student from Temasek Junior College, counts herself lucky that she is leading a normal life despite having GA1.

“With variations in both copies of the gene, the enzyme does not work as it should, leading to a build-up of substances (glutaric acid) that can affect a person’s health,” Prof Tan said.

GA1 is considered rare, affecting about one in every 100,000 newborns worldwide.

Babies with GA1 can appear completely healthy at birth and develop normally in their early months. “Without screening and early intervention, the first sign that something is wrong could be a sudden and devastating metabolic crisis, often triggered by a common illness like fever or infection,” Prof Tan said.

“These crises can cause stroke-like episodes that may lead to permanent brain damage, affecting movements and development. This is why early detection through newborn screening is so valuable – allowing for preventive measures to be put in place before any crisis occurs, protecting the child’s health and development.” When detected early, those with GA1 can develop normally and effectively manage the disorder through strict dietary control, such as having a low protein intake, taking a special medical formula and taking supplements to boost carnitine – a nutrient essential for preventing muscle weakness as well as heart and liver problems.

Regular metabolic monitoring and established emergency protocols in times of illness are also essential for their care.

Mr Lai said: “We researched the condition and it turned out to be very scary. We had to limit her protein intake, otherwise GA1 can cause muscle weakness, spasticity and dystonia (which affect motor skills).” He noted that many individuals with the condition in Singapore are now in wheelchairs.

As for Jia Chi, her condition was caught early enough, preventing brain damage.

SUBCONSCIOUS MIND DICTIONARY DEFINITION:

Having to do with a part of the mind of which one is not fully aware, but which influence ones actions and feelings.

COMMON SENSE:

Two people debating to do or not to do.

CONSCIENCE:

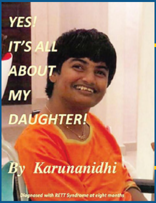
One person telling you why you should have done it or should not have done it.

SUBCONSCIOUS:

Many people telling you something. (thoughts coming into your mind) Practice listening to it and act on it. Subconscious is there to help, no bad intentions.

Mark Twain confided to the world on many occasions that he never worked in his life. All his humour and all his great writting were results of his ability to tap the inexhaustible reservoir of his sub conscious mind.

Source: Malene Institute of Special Needs Studies
1 Nov 2024



YES!
IT'S ALL
ABOUT
MY
DAUGHTER!

By Karunanidhi

Diagnosed with RETT Syndrome at eight months

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